

Stigma and Shame in HIV/AIDS:

Assessing the role of Methodist Church towards PLWHA in Effiduase.

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Master`s Thesis

Master in Diakonia and Christian Social Practice

Word count: 29045

Candidate No.: 6015

15th May, 2020

Declaration

I, hereby declare that this study is an outcome of my research work and findings. Information which were included in the research which were not my own have been acknowledged and references being appended. This research study has not been produce and submitted for academic purpose in any University for an award.

Signature.....

Date.....

Joyce Antwi (2020)

Dedication

I dedicate this research to my sweet husband, Wilson Danso and our lovely kids and to my entire family and friends.

Acknowledgment

“What you have learned and received and heard and seen in me—practice these things, and the God of peace will be with you.” Philippians 4:9

I thank the Almighty God for His direction and protection throughout the period of my study for giving me the strength to overcome all the difficulties that I encountered in accomplishing this study successfully.

I thank my supervisor Prof. Rev. Stephanie Dietrich for her patience, understanding and relevant suggestions which has made this research possible. I also thank the leaders and the entire congregation of Effiduase Methodist church for giving me the opportunity to access their premises and also making themselves available to be interviewed. I also give thanks to my research assistants for their immense contribution for the success of this study. I further express my thanks to my entire course mates and staff at VID Oslo and friends who have supported me in all diverse ways to make my stay in Norway fruitful.

Finally, I thank my spouse Wilson Danso for his encouragement and support for a successful completion of my programme.

15th May 2020.

Oslo.

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Abstract

The purpose of this study is to examine the role of the local congregation in the Effiduase Methodist Church towards people living with HIV/AIDS in relation to stigma and shame.

The study was conducted with the use of qualitative method. The study gathered 12 respondents from the leaders and some members of the congregation for an interview in accessing the role of the Methodist church towards people living with HIV/AIDS in relation to stigma and shame. The research analysed stigma and shame with the use of diakonia and Goffman's theory of stigma.

Effiduase was chosen as the research area due to the fact that the town is located in Ashanti region, which is the second largest region in Ghana and also the second largest infected rate of HIV/AIDS in the country (GAC, 2018). Effiduase as the district capital town is mostly youth dominant as more of the youth migrate from the surrounding villages to the town for economic and other social activities. The youthful population in the region makes the people easily prone to HIV/AIDS and other sexual diseases as a result of the town being located within a region considered to be the second highest rate of HIV/AIDS infection. The high rate of unemployment in the town has been a factor for people to engage in sexual promiscuity especially women in order to fend for themselves. The statistic also shows that the rate of women infection is higher than men in the country therefore, making them vulnerable to acquire the disease (GAC, 2018). The rate of HIV/AIDS infections in the region and its surrounding districts is very alarming and therefore calls for concern.

The leaders of the local congregations formed major stakeholders in working to fight stigma and shame associated with people affected by HIV/AIDS diseases. The local congregations in recent time have become part of the educational agency in raising the awareness of HIV/AIDS and also helping to reduce the impact of stigma and shame by people living with HIV/AIDS (Nicolson, 1995). Unfortunately, some of the leaders of the congregations and its members sometimes, portray negative attitude towards people living with HIV/AIDS with the notion that the disease is transmitted due to unethical sexual practices which is against the doctrine of Christian religion (Chitando, 2007). The findings will impart positively in reducing the stigma and shame surrounding people living with HIV/AIDS through the activities of the church in engaging spiritual, financial support and counselling that could bring hope to people living with the disease.

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List of Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
CBOs	Community Based Organizations
BCC	Behaviour Change Communication
CCG	Christian Council of Ghana
CHAG	Christian Health Association of Ghana
COMOG	Coalition of Muslim Organization of Ghana
EIC	Education, Information and Community
FBOs	Faith Based Organizations
GAC	Ghana Aids Commission
GMA	Ghana Medical Association
GSS	Ghana Statistical Service
HIV	Human Immunodeficiency Virus
NGOs	Non-Governmental Organizations
NSD	Data Protection Service
PLWHA	People Living with HIV/AIDS
SDG	Sustainable Development Goals
UNAIDS	Joint United Nations Programme on HIV/AIDS
WCC	World Council of Churches
YCW	Young Christian Workers
YWCA	Young Women's Christian Association

Chapter one

1.0 Introduction

This research focus within the field of diaconal studies which turns to address the specific roles Christian congregation has in relation to the vulnerable groups in the society particularly people living with HIV/AIDS. The theme for the thesis looks at stigma and shame in HIV/AIDS and the role of the church towards PLWHA. According to Herek and Mitnick (2007), stigma is related to HIV/AIDS in referring to the community's negative attitudes towards PLWHA and related factors. They affirmed that AIDS-related stigma can be defined as prejudice, discounting, discrediting and discrimination directed at people perceived to have HIV/AIDS and at the individuals, groups and communities associated with them. Shame on the other hand, is defined as the feeling that we experiences when we assess and evaluate our actions, feelings or behaviour and conclude that we are wrong (Lewis,1992).

My personal motivation for this research is to see churches serving people within and outside its premises with the same love that God served humanity irrespective of their situation especially the vulnerable groups like PLWHA. Since there has been little or no research on this study particularly in Effiduase in relation to diakonia across churches, my hope is that, the research will be of interest and significance for church leaders (pastors) and congregational members in their role towards PLWHA in a positive manner.

Human Immunodeficiency Virus (HIV) is a disease that causes AIDS. It was first reported in 1981 in America with 36.9million people being affected globally with the disease as at 2017 (UNAIDS, 2017). Globally new infections of HIV have declined or reduced by 47% since the peak of the disease in 1996 from 3.4million infection in 1996 to 1.8million infection in 2017 due to educational campaign and availability of antiretroviral drugs (UNAIDS 2018).

Ghana with a population of approximately 24million people (Population census, 2010) with an area of 239,567km² located in the West region of Africa is one of the developing countries to be faced with the HIV/AIDS epidemic. The early period of the disease were characterised at first by rumours and mystery, followed by the discovery of HIV as a disease in 1986 in the country. The HIV/AIDS prevalence rate in the country is growing up gradually, a situation the Ghana AIDS Commission (GAC, 2018) says calls for concern.

As many good ideas can encounter with insurmountable challenges if people start on the wrong foot, both churches and people living with HIV/AIDS organizations need to be

prepared to work together before starting the common journey of a partnership. Many people living with HIV/AIDS have been stigmatized in their communities and discriminated against in various institutions and sometimes by other churches. The perceptions that churches condemn sinners and promote very narrow guidelines on HIV/AIDS prevention have created negative views in many people in some parts of the word of churches and their response to HIV/AIDS. There is a need for reconciliation for the individual, as well as between individuals and their churches. For this to be possible churches and people living with HIV/AIDS need to be humble, need to be able to listen and be open, forgiving and most of all being able to show true love. A climate of denial regarding HIV/AIDS issues has affected, and in some cases continues to affect some churches and faith-based organizations. Some Christian congregations as well as Muslim-faith community did not believe that HIV/AIDS was a problem in their communities.

The local Methodist church in Effiduase was established in 1961. The church has a substantial number of congregational members in the region. With regards to the church activities to restore hope, providing counselling and spiritual guidance, it became necessary to conduct a research in relation to the role they play towards people living with HIV in diakonia perspective.

Diakonia has been an aspect of the nature of the Christian Church from its conception. The term diakonia comes from the Greek word diakonein, meaning service. This is found in the gospel of Mark when Jesus refers to his messianic mission, as he says: “For the son of man did not come to be served, but to serve, and to give His life as a ransom for many.” (Mark 10:45) Here, Jesus proclaims diakonia as a pivotal dimension of his coming, as the in breaking of God’s kingdom. Diakonia serves as part of the history of the church, and although the organization and content have varied and developed from its beginning, a caring and serving ministry has stood its time. Theologically, diakonia formed part of the mission God gave to his church. To practice diakonia is to serve humanity and through this, also serve God. The church has a mission to care for the people within their community, as well as to care for the people outside. Therefore, one could argue that diakonia should be an integral part of every church irrespective of the form in which it takes in parish life.

This study will examine the role of the local congregation in the Effiduase Methodist Church towards people living with HIV/AIDS in relation to stigma and shame.

Effiduase was chosen as the research area due to the fact that the town is located in Ashanti region, which is the second largest region in Ghana and also the second most infected rate of HIV/AIDS in the country (GAC, 2018). Effiduase as the district capital town is mostly youth dominant as more of the youth migrate from the surrounding villages to the town for economic and other social activities. The youthful population in the region makes the people easily prone to HIV/AIDS and other sexual diseases as a result of the town being located within a region considered to be the second highest rate of HIV/AIDS infection. The high rate of unemployment in the town has been a factor for people to engage in sexual promiscuity especially women in order to fend themselves. The statistic also shows that the rate of women infection is higher than men in the country therefore, making them vulnerable to acquire the disease (GAC, 2018). The rate of HIV/AIDS infections in the region and its surrounding districts has therefore been a call for concern. According to Dr. Emmanuel Tenkorang who is the Ashanti regional Director of Ghana Health Service, (2019), mentioned that, out of the estimated 58,641 people affected by HIV in Ashanti region, 21,828 are currently receiving antiretroviral drugs (citinewsroom.com).

Due to stigma and shame which are associated with people affected by HIV/AIDS in the region, preventions and spread of the disease has become a challenge. Stigmatization is a constant and daily reality that hit the minds of people living with HIV/AIDS in the society. The stigmatization and shame is rooted in the helplessness of people living with HIV and their inability to control or overcome the issue. The disease encourages people living with it to change their socio-cultural practices as a result of their positive status. According to United Nations AIDS (UNAIDS), HIV/AIDS related stigma and shame discourage people to seek information on how to reduce the spread of HIV and to engage in safer attitude in a situation where suspicion about their HIV status is known (UNAIDS, 2010). Most people affected with the disease are not willing to disclose to their family members, friends, local congregation leaders (pastors) with the reason that it could aggravate their predicament than the current situation they find themselves. The stigma and shame associated with people living with HIV/AIDS does not affect them alone but rather extend to their family, friends, and the local congregation they find themselves in.

The leaders of the local congregations formed major stakeholders in working to fight stigma and shame associated with people affected by HIV/AIDS diseases. The local congregations in recent time have become part of the educational agency in raising the awareness of HIV/AIDS and also helping to reduce the impact of stigma and shame by people living with

HIV/AIDS (Nicolson, 1995). Unfortunately, some of the leaders of the congregations and its members sometimes, portray negative attitude towards people living with HIV/AIDS with the notion that the disease is transmitted due to unethical sexual practices which is against the doctrine of Christian religion (Chitando, 2007). According to Chitando (2007), when HIV epidemic first broke out in Africa in the 1980s, the church fuelled stigma and discrimination. The Bible was read to the congregation in a way that condemn people living with HIV. According to Paterson (2005), HIV/AIDS are linked to people's mind with sex, sexuality and sexual orientation which are associated in Christian tradition as sin. This has worsened the stigma that people living with HIV face.

1.1 Purpose of the study

Many people worldwide have accepted these concepts of preventing or reducing the transmission of HIV/AIDS virus; abstinence, the use of condoms, being faithful to your partner etc. One of the critical factors which create an obstacle in fighting the disease in terms of its transmission is stigmatization and shame. According to Kafuko (2009), the stigmatization of people living with HIV/AIDS is as a result of certain perceptions about the transmission of the disease, misconceptions, religious beliefs, social and cultural norms, myth and other factors. The stigmatization is one of the influential factors that make people living with HIV/AIDS to feel shamed and guilt about their status. There are other factors which impede the fight against the spread of the disease such as funds to intensify education and knowledge of the disease, availability of retroviral drugs for people affected by the disease, cultural factors, and perceptions from local congregation and the community as a whole.

As the third goal of the Sustainable Development Goals (SDG) adopted by the United Nations in 2015 which was meant to ensure healthy lives and promote well-being for all at all ages and the declaration of commitment by all members was targeted to promote good health with less or no sickness which HIV/AIDS is included (United Nations, 2015). Even though, various programmes have been initiated by the various nations' leaders including Ghana, in their attempt towards attaining this goal, one crucial issue making it difficult to realize this goal is stigmatization of people living with HIV/AIDS. Despite the existence of HIV/AIDS for such a number of years, stigma and shame have continued to dwell in our society in different forms impeding the various means of responses to mitigate or stop the spread of the disease.

In most cases, infected people may turn to remain silent about their status for fear of being stigmatized which could have negative effects on their lives and prevention of the disease. The local congregation in its diakonia ministry by showing love, care and compassion to the sick and vulnerable in society sometimes expresses negative attitudes towards people living with HIV/AIDS with the notion that they had the disease out of sexual promiscuity which is a sin according to Christian tradition (Chitando, 2007). Stigmatization undermines the effectiveness of individual and the community to fight and protect themselves from HIV/AIDS and even stay healthy while being HIV positive. An international survey of people living with HIV in 2010 revealed that more than one third had experienced loss of employment, denial of health care, social or vocational exclusion. People affected by HIV/ADS in Effiduase are not exceptional to these challenges mentioned above and the region being considered among the recent rising of people infected with the disease, the study will look at the perceptions of the local congregation towards people living with HIV/AIDS, the relationship that PLWHAs experiences with the local congregation, what the local pastors and the congregation doing to integrate PLWHA to reduce or eliminate stigma and shame that are experienced by people affected by the disease.

1.2 Significance of the study

The development of any nation depends heavily on its active and healthy labour force. Looking at the current statistics on HIV/AIDS prevalence in Ghana, the youth are at the high risk of contracting the virus. Stigmatization and shame are common in our society and can stimulate the spread of the disease. The church has been an influential body in its campaign to help reduce the spread of the disease in their various activities. This study will examine negative and positive aspect of the church in relation to people living with HIV/AIDS. The theory of diakonia which emphasis on theological care and service to humans, the vulnerable, the sick and transformation of individuals is a major key in this research. The findings of this research has the intention to redirect the thinking of the church from negative to more positive attitude towards PLWHAs in order to reduce the stigma and shame associated with the disease. My hope is that the research findings will add to the existing knowledge to strengthen the fight against the spread of the disease and as a reference for government, the church and non-governmental agencies as well as individuals in their further research work. More importantly, the findings of this research will be useful to the HIV and counselling units of Effiduase hospital, non-governmental organizations working on HIV/AIDS programmes within the municipality and the Municipal Assembly in general in drawing new

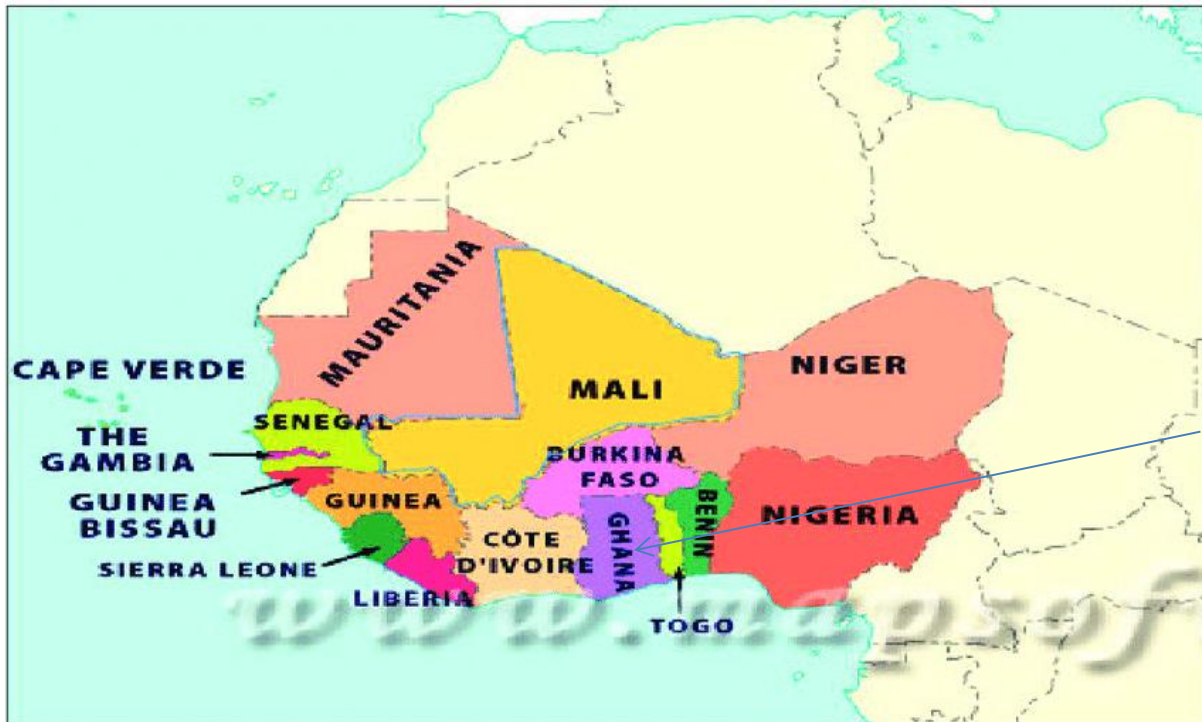
strategies for addressing problems of stigma and shame and also to improve on the existing programmes. The findings and recommendations based on this study will inform policy makers in the study area and the country as a whole.

1.3 Research question

1. What is the role of the church for people living with HIV/AIDS when it comes to stigmatization and shame? Under this research question, I will examine the role of the local Methodist church in Effiduase in mitigating the stigma and shame associated with PLWHA.

1.4 HIV/AIDS Situation in Ghana

Ghana is located in West Africa, sharing borders with Togo on the east, Burkina Faso on the north, and Cote d'Ivoire on the west as shown on the map below.



Map of West Africa Source: Maps of World, www.mapsofworld.com/africa/regions/western-africa-map.html. **Figure1.**

From the merger of the British colony of the Gold Coast and Togoland trust territory, the country became independent in 1957, and became the first sub Saharan Africa to gain independence. Ghana is unitary state with ten administrative regions which are further subdivided into districts. There are currently 216 districts in Ghana which are administered by the districts assemblies.

Ghana with the population of approximately 24million people (Population census, 2010) with an area of 239,567km², with 38.3% of the populace being children below 15 years, it is one of the developing countries to be faced with the HIV/AIDS epidemic. According to the population census in 2010, about 71.2% of the populace are claimed to be Christians, 17.6% are said to be Muslims while 5.2% formed Traditional worship. These three formed the major religious practice in Ghana. Christianity is mainly practiced in the south, Islam being predominant in the north while Traditional worship is spread throughout the country (Anthony J. A., 2009). In spite of Christianity and Islam being dominant in the country, the traditional religious superstitions still permeate in many Ghanaian societies (Anthony J. A., 2009). According to him, most Ghanaians despite their religious and cultural practice perceive people affected by HIV/AIDS as a curse from God.

The discovery of HIV as a disease in Ghana was in 1986. When the disease was diagnosed in 1986, not much was taken into consideration as this case was treated as ordinary health issue. However, with the passage of time, more attention has been given to it due to the effects that come with it. The HIV/AIDS prevalence rate in the country is growing up gradually, a situation the Ghana AIDS Commission says calls for concern (GAC, 2018). According to Ghana Aids Commission (GAC, 2018), education had not been done well to draw people' attention to its testing and prevention. According to Ghana Aids Commission (GAC, 2018), new HIV infections in 2016 increased to 20,418 as against 12,000 new infections recorded in 2015. Again, a total of 15,116 people in Ghana died of HIV and AIDS related illness in 2016 as estimated (GAC, 2018). Furthermore, an estimate of 293,804 people are living with HIV out of it 89% are adults and 11% are children (GAC, 2018). Among people living with HIV/AIDS in Ghana, 178,560 are females who formed 61% and 115,244 are males who formed 39% (GAC, 2018). According to Ghana AIDS Commission, the prevalence of HIV/AIDS among the youth in 2017, especially those below the age of 24, rose to about 45% nationwide. The Commission attributed the upsurge to unprotected sex as well as low knowledge of the youth about the infection. According Ghana AIDS Commission (2018), a total of 15,116 people in Ghana died of HIV and AIDS-related illness.

Despite these challenges facing the country, Ghana is still considered as one of the lowest rate of HIV/AIDS infection in the sub-region of West Africa with adult HIV prevalence of 1.6% (UNAIDS, 2014). Antiretroviral therapy (ART) coverage in the country suboptimal, with about 34% of all HIV/AIDS infected people receiving ART (UNAIDS, 2014).The country is increasingly faced with difficult decisions on optimizing ART treatment strategies

that are effective, efficient and feasible within the context of stagnating international donor contributions.

The fight against HIV/AIDS in Ghana is not limited to National AIDS and STI Control Programme but rather other stakeholders are involved in this fight such as Christian Health Association of Ghana (CHAG) comprising the Salvation Army, the Catholic Secretariat and the Presbyterian Church, denominational associations, ecumenical organisation, and the Muslim community. They are strongly involved through creation of awareness, education for the moral and spiritual integrity of the people. Other stakeholders like the private sector and Non-Governmental Organisations which mainly intervene through awareness-raising information activities. Mental and societal health issues are couples of sicknesses that are related to stigma and shame in our community following HIV infection. For instance, mental disorder as was researched by GMA (2015), cuts across all age, education, sex employment, ethnicity and marital status. The study shows that more females were stigmatized than males at work and educational level. Various forms of stigma were observed from mental disorder which was not different from stigmas that are experienced by PLWHA which also need to be addressed.

1.5 Effiduase/Sekyere East District

Effiduase/Sekyere East District is one of the 30 districts in the Ashanti region of Ghana. Effiduase is the district capital. Below is the map location of Effiduase in the Ashanti region. The district has a population of about 62000 representing 1.3% of the entire population in the region (Ghana Statistical Service, 2014). According to the 2010 population and Housing Census in Ghana, about 54% of the population in the district lived in urban areas while 46% live in the rural areas. This means that most of the youth in the district migrate to Effiduase as the capital town for economic and other recreational activities. The occupational distribution of the district indicates that 42.3% of the population are skilled farmers who are engaged in agriculture, forestry and fishing, 22% of the populace are into services and sales while 14% are engaged in craft and other related services (Ghana Statistical Service, 2014). According to Ghana Statistical Service, (2014), the literacy rate among the populace is 84.2% who are mostly 11 years and above while about 14% of the population who fall on the same age group is non-illiterate. In Effiduase/Sekyere District, about 13.4% have never been to school, 44% are at school while 42.5% have attended school in the past.

Figure2. Below shows the map of Effiduase as the research area.



Source: (Ghana Statistical Service 2014)

1.6 Organisation of the study

This thesis is designed in six main chapters with chapter one covering the introduction to the study, purpose of the study, the significant of the study, research questions, HIV/AIDS situation in Ghana, Effiduase/Sekyer District and the organization of the study.

Chapter two of the thesis covers theories on stigma and shame, literature review relevant to the general studies on stigma and shame in HIV/AIDS. The chapter also puts emphasis on the theoretical framework used for the study.

Chapter three of the thesis covered methodology and the study area. It also entails research design methodology used for the data collection from the field, sample size and source of data. The ethical consideration and limitations of the study were also discussed on this chapter.

Chapter four covered presentation of findings from the research, the role of the local congregation towards PLWHA by considering the positive and negative aspect, how the people affected by HIV/AIDS experience and perceived the role of the local congregation. It also examines the impacts of stigma and shame against people living with HIV/AIDS.

Chapter five covers analysis and discussion of the findings. It looked at the presentation of the findings, analysis and discuss of the data. Chapter Six covered conclusion and recommendations that were drawn from the findings of the study.

Chapter Two

2.0 Theories

This research makes use of existing theories and concepts. The same way as the methodology and research question which were taken for the thesis. The results are affected by the theories which have been ascertained and analytical frameworks based on those theories. The research adopted two analytical approaches to address the research question and linked it to PLWHAs and the role of local congregation towards PLWHA. This chapter also contain literature review relating to some of the main concepts found in the research topic and studies which have already been done which are similar to the topic and how it was studied.

2.1 Theories of stigma and shame

There are various forms in which people living with HIV/AIDS experience stigma and shame. The specific expressions of stigma varied within settings, but the most common experienced forms similar across countries that are directly experienced by people living with HIV/AIDS themselves, noting where there are particular gender differentials. However, many of the forms of stigma described below are also experienced by people closely associated with those living with HIV/AIDS, such as family including spouse and children and other caregivers. The forms and degree of stigma also change over the course of an infected person's experience with HIV and AIDS (Bond et al. 2003).

2.1.1 Stigma in relation to HIV and AIDS

As this study has already established, 'stigma' was in use long before HIV/AIDS was discovered. When HIV/AIDS came onto the scene, it joined a list of many other situations such as slavery, physical disabilities and foreignness by which people were stigmatised. According to ICASA (2003), stigma in the context of HIV/AIDS can be linked back to the time when HIV/AIDS was first discovered, and to the subsequent identification of high-risk groups as being the majority of individuals initially infected by HIV. In addition, stigma is related to HIV/AIDS in referring to the community's negative attitudes towards PLWHA and related factors.

One can also say that the relationship between HIV/AIDS and stigma has to do with the nature of the disease, and is caused by the fear of certain factors surrounding HIV/AIDS such as rejection, isolation and labelling of people affected by the disease and their friends, families, fear of infection, misunderstanding of how infection occurs, associating HIV with immorality, and fear of death (Dube, 2007). This results in treatment, mostly associated with the sexual method of HIV transmission and the fact that it is known to be a deadly disease, which imposes 'invisible marks' on PLWHA which makes them being labelled as unworthy of any consideration in the society and also make them to feel depressed. According to Baldwin (2005), PLWHA are often stigmatized as a result of their health status. This attitude may be caused by the fact that the diagnosis of HIV/AIDS is usually associated with sexual immorality.

According to Swann Jr. (2008), the Academic Education Development Centre on AIDS and Community Health defines HIV-related stigma as follows:

HIV and AIDS stigma refers to all unfavourable attitudes, beliefs, and policies directed toward people perceived to have HIV and AIDS as well as toward their significant others and loved ones, close associates, social groups, and communities. Patterns of prejudice, which include devaluing, discounting, discrediting, and discriminating against these groups of people, play into and strengthen existing social inequalities especially those of gender, sexuality, and race-that are at the root of HIV-related stigma.

Swann Jr. (2008) further indicated three categories of HIV/AIDS stigma:

- Instrumental HIV-related stigma: a reflection of the fear and apprehension likely to be associated with any deadly and transmissible illness;
- Symbolic HIV-related stigma: the use of HIV and AIDS stigma to express attitudes toward the social groups or lifestyles perceived to be associated with the disease;
- Courtesy HIV-related stigma: stigmatization of people connected to the issue of HIV and AIDS or HIV-positive people.

To explain this further, these three categories of HIV/AIDS stigma can be put into two categories: ‘specific’ and systematic. On the one hand, HIV and AIDS-related stigma is described as specific when it is directed toward a specific person or group of people while ‘systematic’ when it does not necessarily need to be directed toward a specific individual in order to have an impact. Specific HIV/AIDS stigma is actively shown while systematic HIV/AIDS stigma is passively manifested. Systematic HIV and AIDS-related stigma is also born out of personal histories, beliefs, fears, biases and prejudices, and combines with the images, messages, stories and myths individuals have experienced and continue to experience, to produce a mind-set about the illness. As far as the impact is concerned, systematic HIV and AIDS-related stigma informs and motivates specific HIV and AIDS-related stigma, as individuals are required to make decisions for themselves or about others in situations where HIV and AIDS is an obvious issue.

According to Herek (2005), HIV/AIDS-related stigma refers to the “prejudice, discounting, discrediting, and discrimination directed at people perceived to have HIV/AIDS, and the communities with which they are associated.” The relationship between the HIV/AIDS disease and its impact on individuals, families, communities, orphans, the private sector, economic growth, and government has been duly noted. Because of this complex nature of the disease, it is without doubt that any researcher to study the sociology of HIV/AIDS is likely to become amazed by the social nature of the disease. However, critical analysis of

this “social nature” can result in broad themes that connect the literature together. One such theme is the way in which stigma influences those living with it and the disease.

Stigmatization is a discreditable and unpleasant issue for people living with HIV/AIDS which makes them vulnerable and debased. It is a daily reality that continuously strikes in the minds of people living with HIV/AIDS. According to Lekganyane and du Plessis (2011), stigma can be felt which leads to an unwillingness on the part of the persons being diagnosed to seek assistance and to access medical and other sources of resources. It can also be enacted (external stigma), leading to discrimination on the basis of one's HIV status. Stigma can either be external or internal. External stigma refers to the actual experience of discrimination whereas internal stigma (felt or imagined stigma) refers to the shame associated with people living with HIV/AIDS with the fear of being discriminated against. Internal stigma is rooted in the helplessness of PLWHAs and their lack of control over the situation. Internal or self-stigma fosters PLWHAs to change their socio-cultural practices due to their positive status. According to Herek et al. (1988), HIV/AIDS is highly stigmatised because it is a disease that is perceived as the bearer's responsibility because the primary modes of transmission of the infection are behaviours that are considered to be of choice. The antithesis to this symbolisation is that of the innocent person with HIV/AIDS, infants and young children, who are commonly positioned as the devoid of any blame, shame or guilt with respect to their infection. The distinction between innocent and guilt associated with people living with HIV/AIDS is underpinned by the strong emphasis upon the association between lifestyle choices and health states that has emerged in the medical and public health discourses over the past few decades. According to Shisana (2004), stigmatisation can be defined as categorising someone that labels him or her in an undesirable manner. Shisana further argues that the outcome of stigma leaves the individual with a feeling of being responsible for his or her undesirable status. HIV/AIDS is not limited to being a health problem alone but rather a social, psychological and spiritual problem. The disease affects the person on how he or she relates to others and how he relates to God. When people are tested with the disease, they become aware of the consequence and the anticipated reaction that might come from society due to the fact that, they themselves have probably ever engaged in negative comment against those who were affected with HIV/AIDS before. For this reason, many are discouraged to freely go for a test to know their HIV status for fear of psychological trauma. Stigmatisation and shame are one of the biggest obstacles to HIV prevention for individuals, communities as well as political, business and religious leaders. Clergy, with HIV have been dismissed from

their jobs, and shunned and ostracised by members of their religious groups, people living with HIV/AIDS and their families have been excluded from churches and their various places of worship, publicly exposed, refused pastoral care and funeral rites, and in extreme cases, have been killed.

According to Chitando (2007), very few churches in Africa have succeeded in providing hospitable space to those living with HIV/AIDS. In most cases, the preaching continues to engender stigma and shame. Many local pastors continue to mock people living with HIV/AIDS. For instance, Canon Gideon Byamugisha, an Anglican priest from Uganda who openly disclosed his HIV status at the World Council of Churches (WCC, 2006) said, such preachers want to use AIDS to control the church. Instead, they should be using the church to control AIDS. Messages that seek to scare people have proven to be ineffective.

2.1.2 Shame in HIV and AIDS

The concept of shame is characterized by so many different approaches. According to Pattison (2000), there is no experience or meaning that underlies all usages and instances of the category 'shame'. Shame is made up of enfolded and overlapping, but also discrete, meanings and understandings; this implies that there is no universal set of concepts in which all experiences of shame can be translated. According to Lewis (1992), he defined shame as the feeling that we experience when we assess and evaluate our actions, feelings or behaviour and conclude that we are wrong. The wrongness that we admit to ourselves covers the whole of ourselves; which compels us to hide, to disappear or even choose to die. The willingly desire to avoid thinking about shame might be supported by the 'filthy' nature of it. While shame may follow from stigma, whose function may be to elicit shame in the recipient, not all individuals who are stigmatised experience shame.

Despite the definition given above, the concept of shame can be expressed in two folds in order to understand its meaning and purpose; it denotes positive and negative connotation. We have discretionary shame which emphasizes on positive aspects and disgraced shame which lays emphasis on negative.

2.1.2.1 The discretionary shame

The discretionary shame carries the functional aspect which every individual is embedded with. It is the type of shame which relates to the privacy of the individual which helps us to hold on to an appropriate standard and boundaries in relation to other people. This function of

shame demonstrates the positive aspect of it in terms of preserving dignity in our social context. According to Albert (1995), discretionary shame has the positive function of ensuring modesty, privacy and prudence. It functions by creating appropriate boundaries in order to protect against intrusive actions which can violate the dignity and integrity of another person. For instance, it is appropriate for one to urinate but not acceptable and also shameful to urinate in public. In this situation, a person who is ashamed to urinate in the public is always accorded with respect as against the shameless person who will urinate in the public at the watch of others. With this illustration, Albers (1995), considered the concept of shamelessness to suggest that the lack of a proper sense of shame is a moral deficiency and that the possession of shame is a moral obligation. This type of shame can be used to different types of life situations that can only be done in private.

For the purpose of this thesis, disgrace shame will be use instead of discretionary shame when references are made on shame.

2.1.2.2 Disgrace shame

According to McNish (2004), shame has reference to the needs, desire, situation and condition of the body. It deals with self-consciousness which means that irrespective of what one has done or not done, it makes one to feel valueless or worthless. Lewis (1992), in his accession, shame becomes ‘self-problem’ while guilt remains ‘action-problem’. For instance, Lewis (1992), gave a scenario of “‘stop! You are not good”’ to indicate that it is the person or ‘oneself’ which carries the problem unlike guilt which indicate the ‘action’ of the person being the problem. Disgrace shame thus, explains well under the context of people living with HIV/AIDS. The concept of shame presents itself with challenges to deal with. In the situation of guilt, one just has to deal with the challenge by changing one’s actions and doing better actions. Moreover, in guilt there are established social and religious rituals which can effect restoration of a guilt person. In the case of shame, as was said by Lewis in Albers (1995), “‘it is about self, not action; thus, rather than resetting the machine toward action, it stops the machine. Any action becomes impossible since the machine itself is wrong”’.

Shame makes the person feels valueless and unworthy. The shamed person has the tendency of hiding his or her devalued identity. This means that when a counsellor from the church or local congregation is presented with the person shame based identity, he or she will have a big challenge of having dialogue with the person unless the issue of shame is well addressed. The problem or challenges of shame is well summarized by Albers in a paragraph when he

says: “the ‘self’ views the self from the shame perspective and alike a malignancy the shame metastasizes to permeate the entire person physically, emotionally, socially, and spiritually. Furthermore, shame often has the malignant effect of extending its tentacles to encompass others who are related in a significant fashion to the shame based person.the individual possessed by a shame perspective and perception believes there is no way back to the mainstream of life” (Albers, 1995).

2.1.3 Shame and Guilt

The concept of shame and guilt will be discussed in relation to people living with HIV/AIDS. This chapter will examine if shame and guilt in people living with HIV/AIDS has its source also from the teachings of the local congregation apart from the other sources of their shame and guilt. The concepts, shame and guilt are completely different in meaning but are mostly used interchangeably. In trying to differentiate the two concepts, I will define the two terms.

Guilt is normally the negative feelings that one experience from doing an action. Every society has its own moral standards that governed whether an action is morally acceptable or not. That is, whether an action is right or wrong. This has been structured into our culture and religion since the olden days. When one go against one or more of these moral standards, one usually feels bad and show some sign of regret or guilt. According to Albers (1995) illustration of guilt, if one hear the command ‘stop!’ what you are doing violates the standards or rule. Pay attention to what you did and alter your behaviour”. In guilt, it is the wrong action done or the right thing not being done which give rise to the bad feeling. One feels guilty when he or she thinks that what he or she has done is not permissible in his or her culture and religion.

False guilt is the bad or negative feelings that one experience without doing anything wrong. It is the same negative feeling that a person who has committed wrong thing may feel, yet without doing anything wrong. In certain situation, people take responsibility of wrong actions committed by others. Instead of defending oneself from wrong things they are not responsible, they rather blame themselves for the wrong action and feel guilt as a result. The cause of the negative feeling attached to false guilt may not be known, but the feeling of it is equally strong or even stronger than those caused by wrong action. This false guilt feeling in most cases is being combined with bad self-image. In most cases, people with low esteem and are less important are those likely to take upon themselves of guilt whose wrong actions are done by others. Shame on the other hands, involve issues with self-imaging and self-

consciousness. Even though, shame and guilt are two different concepts, they are mostly related. This makes it necessary to link guilt with stigma in this study. Many people living with HIV/AIDS were infected with the disease through no fault of them and are innocent for the contraction of the disease but most of the time feel guilty and blame themselves as being the cause of their infection.

2.2 Church

The term church anytime it is used in this research means the local congregation of people of God or local community of people who believe in God.

The word church comes from a Greek word *ecclesia* in the Bible which means assembly. Church is usually referred to as people whenever it is used in the Bible. It can be used as mob to mean church in (Acts 19:30-41), or used as the children of Israel also in (Act 7:38) and the body of Christ in (Ephesians 1:22, 5:25, 32). The word church has been used in three different ways in the Bible. In the first place it is used as the body of Christ, which describes a local assembly or group of believers this, can be found in (Corinthians 1:2, and 2 Corinthians 1.1). The church again was described as the body of the individual living believers and finally it is defined as the universal group of all people who have trusted Christ through ages in (Matthew 16:18) and (Ephesians 5:23-27) (Williams, 2014).

Williams (2014) attest that the church has a spiritual purpose for the local church or the assembly of believers and has different roles that God gave to people of believers for the purpose of perfecting or training the believers to do the work of the ministry and to strengthening of the church body. The roles given to people are apostles, prophets, evangelists, pastors, teachers and deacons.

Again, Velarde (2009) confirmed that the church is not a building but a body of believers with a specific nature and purpose because the early Christians had no buildings. There are many roles to be performed by the church but the most important ones are worship, edification and evangelism. He went on to further explain that worship is God and Christ centred.

According to Clugston and Holt (2012), the church is both human and a divine institution with the purpose to promote and sustain the image and dignity of all people. It is assembly, family or community of God; it is also trans-cultural and transnational and therefore must be involved in the process of integral human development because it plays important roles in

spiritual and moral development. This is done through its socio-economic and pastoral interventions to promote human development to prevent poverty, improving lives and livelihood access to make the world a peaceful place to live and positive development. The primary aim of this study is to look at the local congregation and its role related to HIV infected people. That might include both regular worship and proclamation taking place there, looking at the moral teaching by the church pastors, moral standards uphold within the congregation or by its members, community life, fellowship experiences within the congregation and the congregation's presence in the local community through diakonia.

2.3 Theory of diakonia

I will now present some key understandings on the concept of diakonia. I will first look at the theology of diakonia, the understanding of diakonia as being the church. I will again look at the concept of empowerment and care which form key aspect of diakonia which will be used as part of theoretical framework for the research. I will also briefly bring in some perspective on diakonia within the church service.

2.3.1 Theology of diakonia

When developing a theology of diakonia, there are many different perspectives one can follow. One can see that throughout Christian history, diaconal action has been a response to concrete situations of suffering, need, marginalization and injustice.

As a faith-based action, Diakonia demonstrates, by the use of examples in the Bible, to indicate the importance placed on understanding a context before diaconal work can initiated as seen in the Lutheran World Federation (2009)- "the Bible announces God's action in the world within specific historic contexts and very often where there is human suffering". Therefore, diaconal action is understood to be context specific and requires greater effort to gain an in-depth knowledge of the complex and multifaceted nature of the context through an interdisciplinary approach. The church should therefore always be sensitive to human reality, the challenges that threaten human dignity and life. We see this in the story of Jesus feeding the five thousand; people were without food, but the disciples only started acting when Jesus instructed them to give the people something to eat (Matthew 14:16). Jesus instructed his disciples to be aware and act on human need.³⁵ Martin Luther conveyed that there is no need for Christians to create good deeds, because it comes to us in the form of everyday challenges. This is what is referred to as "spontaneous" diakonia (Nordstokke, 2011). This is

not to say that there is no need for organized diaconal actions, contrarily, the church must be aware that there are peculiar challenges and needs that demand diaconal actions to be organized.

2.3.2 Diakonia as being the church

There is no precise definition of what diakonia is, however, there are some basic assumptions. One of these is found in *Diakonia in Context: transformation, reconciliation, empowerment* is a document published by the Lutheran World Federation in 2009. Without giving a specific definition, it maintains some fundamental assumptions when understanding diakonia:

One is that diakonia is a theological concept that points to the very identity and mission of the Church. Another is its practical implication in the sense that diakonia is a call to action, as a response to challenges of human suffering, injustice and care for creation. This rather open-ended understanding of diakonia is also due to the fact that the concept itself does not allow for a precise definition, not even when used in the Greek New Testament. The present use of the word has largely been shaped by how Christians have tried to be faithful to the biblical call to be a neighbor throughout the history of the church.

The concept of diakonia has transformed over the last decades, particularly within the ecumenical movement. There are three main attributes that characterize this change. First, let me point to the ecclesial dimension of diakonia. Diakonia has become a part of the nature and mission of the church and stepped away from where it stood earlier, as work for the professionals and agencies. Now, diakonia has become a part of being the church, and has strong focuses on the biblical dogmatic foundation of diakonia and is oftentimes is linked to missiology (Dietrich, et al., 2014). The second attribute that characterizes this change is that diaconal actions must be holistic. It takes physical, mental, social and spiritual dimensions into consideration, and dismisses practices that tend to departmentalize sectors of human reality. The third is the prophetic, the bold diaconal action in solidarity with suffering and marginalized people. This has moved diakonia from the traditional conceptualization of humble service for a limited few, to a central and highly influential aspect that commissions every believer (Dietrich, et al., 2014).

The care for others should not be only professionalized and institutionalized but motivated personally and to the community in which it is embedded. Diakonia as the Gospel in action;

as Jesus brought the Gospel in both words and deeds, his disciples were mandated to follow in his example. Diakonia is therefore an integral part of the gospel, and speaks to the dimension of being the church.

The concept and theory of diakonia of the church encompasses the call to serve the poor and oppressed, to address the issue of injustice and to fight in order to restore the value and dignity of all human races irrespective of their sex (Stephanie Dietrich et al., 2016). Diakonia thus contributes to empowerment, reconciliation and transformation. Diakonia emphasised much on human experience as critical for the development of its theories in order to improve diakonia practice. The Church of Norway Plan for Diakonia, came out with this definition of diakonia as: *the caring ministry of the Church. It is the Gospel in action and is expressed through loving your neighbour, creating inclusive communities, caring for creation and struggling for justice.* Diakonia is therefore an integral part of the gospel, and speaks to the dimension of being the church. This explanation points to the traditional acts such as caring for your neighbour but also refers to creating inclusive communities, caring for creation and struggling for justice (Dietrich, et al., 2016).

Diakonia talked much on unjust power, oppressive practices and marginalization. It also involves the participation to fight for a just and equitable distribution of resources. Such sharing of resources is accompanied with mutual responsibility and accountability of churches and ecumenical partners. The key concepts embedded in the theory of diakonia; ‘empowerment’ and ‘care’ are the main tools used as the framework in understanding the role of the local congregation towards people living with HIV/AIDS in terms of empowering and giving care to people affected by the disease.

2.3.3 Pastoral care for PLWHA

Pastoral care is one of the theoretical frameworks for this research. With regard to caring for people living with HIV/AIDS, it is very relevant that the local Church initiate such care. Church ministry, directed toward PLWHA in the form of diakōnia, is particularly useful in Effiduase locality, which faces high prevalence rate of HIV/AIDS in the country. Since HIV/AIDS has become a dominant among the youth and women due to poverty in the region, it is very important to establish a pastoral care approach that equips the Church to deal with this challenge. In communities where HIV/AIDS prevalence is very high, clinic and hospitals are often overcrowded with HIV patients, and it is difficult for them to get

admission into health facilities because wards and rooms are mostly occupied (Slattery, 2008). In that situation, another strategy could be developed through which PLWHA could be given home-based care. In this regard, Winkler (2004), provided two vital reasons why care and support in the home can be a very important part of the response to the HIV/AIDS epidemic. The first reason according to Winkler, is that many health care practitioners feel that clinics and hospitals should focus on treating people in the early stages of the infection till when the affected person's immune system has become weak to fight the infection and has developed into AIDS, then it is appropriate for that person to be cared for at home. The second reason is that there is increasing evidence that the care and support given to families living with HIV do not only help them to improve the quality of their lives, but also strengthens the HIV prevention services in the community, which then increases the capacity of families to care for the affected person.

Van Dyk (2008), further defines home-based care as the care given by a family member or friend (the primary caregiver), supported by a trained community caregiver, in the home of the person living with HIV/AIDS. According to Van Dyk (2008), also emphasised the need for home-based care as a relevant approach of care for PLWHA, with the aims:

- To empower the community and the family to cope effectively with the physical, psycho-social, and spiritual needs of those living with HIV infection and AIDS;
- To educate the community about the prevention of HIV transmission;
- To support family members in their care-giving roles; and
- To reduce the social and personal impact that living with HIV infection and AIDS makes on all those concerned.

In this regard, the family can provide a safe place for care and disclosure. As has been noted, home-based care can be an effective tool to care for PLWHA in their homes, as individuals are more comfortable receiving care at home than in hospitals. The local church leaders in Effiduase can engage in pastoral home-based care in their churches according to the following principles, as pointed out by Magezi & Louw (2006):

- A congregational systems approach, which does not view a believer in isolation, but within a network of relationships, should be encouraged. The sick and suffering HIV person that embraces Christian modes of healing and refuses African traditional modes, and is in conflict with the network of the extended family, should find a support base through congregational members. Congregational (family) home-based

care, therefore, should be ready to supplement or, where necessary in extreme cases of exploitation, replace traditional family care to facilitate the therapeutic process

- Congregational members should be patient with members who struggle to embrace Christian modes of healing. One must always keep in mind that it is a painful decision to distance oneself from the extended family. Jude's words are apt: "Be merciful to those who doubt" (Jude 22).
- In order to be sustainable, congregational systems of care should always try to assist affected members to keep connected to their blood relatives (family and community). When such members successfully overcome the crisis, they can exhibit and testify to God's victory and hope to the rest of the extended family, thereby becoming salt and light in this world (Matt. 5:14-15).
- Congregational care in poor communities should generally be sensitive and be aware of the immense need of its people and those in the community. As an institution, it should stand between the informal home-based care providers and outside agencies that provide resources in order to holistically support its members and the community. Pastoral care cannot and should not ignore the plight of the needy.

As for the models of home-based care, Uys and Cameron (2003) distinguish between two types of home-based care: integrated home-based care links all the service providers (clinics, hospitals, support groups, social workers, non-governmental organizations, [NGOs] etc.) with patients and their families in on-going care; single home-based care, on the other hand, is about one service component (a hospital, an NGO or a church) organizing home-based care by recruiting volunteers, training them, and linking them with patients and their families at home. Informal home-based care is about families caring for their members at home without any form of training or external support, but with the informal assistance of their own social network. It is preferable that the Church strive to provide home-based care through an integrated model, since this approach ensures that the patient and family get all the help they need, from the day the diagnosis is made, through all the phases, to terminal care, even after the death of the patient. To further emphasise the design of a congregation's home-based care, Magezi and Louw (2006) make use of African communalism concept. This concept is commonly called 'Ubuntu' which means 'humanness'. It embraces the values of non-discrimination, sharing, cooperation, cohesion, goodness and dignity in the daily interactions of the community. Ubuntu is therefore the quality of being human through other human beings. For this reason, it is an invaluable building-block contributing to successful and effective congregational home-based pastoral care. The concept of ubuntu is common in

Africa and even in Effiduase where people live with their relatives. Adopting such a system of care means that the Church does not just care for the individual, but also for the family, because an individual only exists in a family setting. This is to say that the individual also benefits, so everyone can share the care provided to them. In order for the Church to be effective in this, it should train families in caring for their members. This means that the efforts of the Church in providing an opportunity for the family to care for their own members who are suffering will include training to provide families with the skills to offer care to the loved ones who face suffering (WCC, 1997). This implies that when caring for individuals, it is important that the whole church be involved, each member having a part to play, rather than giving an opportunity only to those regarded as experts. It must be realised that each one in the congregation should have something to do, however small, to help PLWHA (Richardson, 2006).

2.4 Goffman's theory of stigma

In relation to the impacts of internal stigma of people living with HIV/AIDS, Goffman's theory of stigma is applied as part of theoretical framework in this study. Erving Goffman was a Canadian-American Sociologist, Social Psychologist, and a writer. He was born in 11th June, 1922 and died in 19th November, 1982. He was considered among the most-cited author in the humanities and social sciences. He was 73rd president of the American Sociological Association. Among his best contribution to social theory is his study of symbolic interaction. Goffman's main areas of study included the Social Interaction, Sociology of Everyday Life, the Social Construction of Self, and some element of social life such as stigmas and total institutions.

Goffman defined stigma as "...a powerful social label, stemming from a discrediting attribute of the individual which radically changes their social identity" (Goffman, 1963). Goffman's primary concern was, however, not with such long-term adjustments, but rather with the way in which stigma bearers interact with non-stigmatized when they are in one another's immediate physical presence, 'whether in a conversation like encounter or in the mere co-presence of an unfocused gathering.'

Stigmatization is related to those illnesses that are incurable, fatal and extreme. In our social context with an individual perceived or known to have a stigma, we are likely, then, to use categorization that do not fit, and we and the affected person of the disease are likely to

experience uneasiness (Goffman, 1963). And since the stigmatized person is likely to be more often faced with these situations than are we, he is likely to become the more adept at managing them (Goffman, 1963).

Goffman identified three strategies in his theory of stigma which evolve: passing, covering and withdrawal, which are used to cope with a stigmatizing attribute in our social contexts. These strategies are not different to stigma bearers but whereas they may be used occasionally be normal when their identity is in danger or insecure; they must be used continually by stigma beaters. According to Goffman, a discrepancy in such a situation may exist between an individuals' virtual and actual identity. These discrepancy, when known about an apparent, spoils his social identity, it has the effect of cutting him off from society and from himself so that he stands a discredited person facing an unwelcoming world (Goffman, 1963). In the context of HIV/AIDS, stigma and shame as "a process of devaluation" because in some cases, as with the person affected by the disease, he may continue through life to find that he is the only one of his kind and that the entire world is against him. HIV/AIDS has been stigmatized because it can be fatal and therefore causes fear; it is often associated with behaviour that is already stigmatized, such as sex work, infection is seen as the result of "choices" made by an individual (e.g., the "choices" to have unprotected sex or to share needles to inject drugs) and it is seen as punishment for "deviant" behaviour (Bollinger, 2002).

I chose Goffman's theory of stigma as one of my theoretical framework in a sense that HIV/AIDS stigma emanate from social perceptions of physical characteristics, aspect of character and 'tribal' associations such as race, gender etc.

Chapter Three

3.0 Profile of the study area and Methodology

This chapter provides the profile of the study area related to the theme of the research and discusses the methods adopted in the research work. These include the target population, sample size and sampling, sources of data, instruments and techniques of data collection as well as tools for data analysis.

3.1 Profile of the study area

The study was conducted in Effiduase in the Effiduase/Sekyere District of Ashanti region, Ghana. Effiduase is the capital town of Effiduase/Sekyere District in the Ashanti Region of Ghana which serves as the meeting point for several economic and social activities. As the district capital, it serves as a market centre for the rest of the small towns and communities surrounding it. Additionally, it serves as a place for other recreational engagement and interaction.

3.1.1 Health Facilities

Effiduase/Sekyere District is not different in terms of health challenges that are encountered in other parts of the country. The district has one main district government hospital situated in Effiduase, another hospital at Asokore, three clinics with two situated in Effiduase, three health centres and eighteen CHPS serving the entire area. The district lacked many health facilities that are fundamental in promoting good health service. For instance, there is no mental health centre to serve patients with mental challenges and the available scarce facilities are not able to serve adequately to the people in the region. There is an issue with professional personnel manning the health situation in the district. For instance, the doctor to patient ratio in the Effiduase/Sekyere District of Ashanti Region which consists of 38 communities, with a population of 85,702 with four sub-districts namely Asokore, Nyanfa, Mponua and Effiduase stands at 21, 426 in 2010 according to Mr Dominic Dobbin, the District Director of the Ghana Health Service. This situation has made it difficult in accessing treatment for people affected by HIV as there are limited facilities at their disposal and qualified health workers to manage the facilities and also care for the sick suffering from HIV and other related diseases. For instance, limited healthcare facilities, limited antiretroviral drugs, compelled PLWHA to spend much time at the hospital and mostly in a queue which exposes them to visitors and other patients who come to the hospital for other treatment considering the social stigma associated with the disease.

3.1.2 Economic activities

The major economic activities in the Effiduase Sekyere district are retail trade, farming, small scale agro-processing and other trades such as carpentry, metal fabrication, tailoring, and hair dressing among others.

Agriculture activities in the district are basically subsistent in nature and the farmers mostly rely on traditional labour rudimentary farm implements. The major tree crops in the area are citrus, oil palm and cocoa. Other root and tuber crops cultivated in the area are cassava, yam and cocoyam. The area is also noted for its cultivation of cereal products like maize and rice.

Various livestock are reared in the area these include poultry, goat, pig, sheep, cattle, grass-cutter and snail. However majority of these animals rearing are on small scale basis under free range system.

Even though the district does not have any large scale processing industry, the district can boost of some small scale industries such as palm oil, palm kernel oil extraction, soap-making, pottery and weaving in some communities. For instance, at Asokore, there is a women co-operative society which uses an extraction machine to extract palm-oil and palm kernel oil.

The district has some mineral deposits at Ntunkumso and its environs, Attakrom and along Anunuso river banks. Sand winning activities are also widespread in the district. Areas noted for sand-winning include Odurokrom, Okaikrom, Asokore, Senchi and Effiduase. There are over four hotels operating in the district. Traditional caterers, drinking bars, restaurants, as well as fuel stations abound in the district; Effiduase and Asokore have post offices and telephone services available across the district. Financial services are provided by three banks and other micro finance institutions in the area. The relevant of the economic activities in the study area, provide information of the available jobs for members in the community and some of the possible job lost that can hit against PLWHA due to stigma. The economic contribution of the member afflicted with HIV and AIDS is reduced or completely halt, which results in a severe difficulty to the family and also causes this member to be blamed for the financial difficulties the family goes through (Maughan-Brown, 2007). When people infected by HIV develop full-blown AIDS, they become less productive which result to less income, thereby causing families to become very poor, some even breaking up while others endure the burden of care for very sick relatives and orphans (Winkler, 2004). This virtually rendered most of the PLWHA to poverty. At this level, becomes imperative for the local congregation to show their love, care and support to the needy especially PLWHA.

3.2 Research design and methodology

This chapter describes the methods that were used to collect data for the study. Qualitative method was employed in the collection of data for the study with the use of other approaches like interview, primary and secondary data collection, transcription etc. Interviews were conducted with some key members in the local congregation, some members of the local congregation and PLWHA within the local congregation. Qualitative interview was used with a total of 12 respondents with 3 female respondents of PLWHA, 3 male respondents of PLWHA, 2 leaders (local pastors) from the local congregation and 4 members in the local church.

3.2.1 Methodology

According to Creswell, J. W. (2014), Methodology involves the procedures and techniques being adopted in understanding the meaning and concepts that people ascribe to a social or individual problem in a scientific approach. Selecting a particular scientific method and techniques to solve a research problem defines methodology. This implies that, the fundamental of a research, depends on the choice of method being adopted by the researcher which also provides much knowledge about the research problem. The research will be conducted with the use qualitative data collection method. According to Flick et al., (2004), qualitative method of data collection describe a phenomenon “from the point of view of people who participate to contribute to a better understanding of social realities and to draw attention to processes, meaning patterns and structural features”. The study uses a qualitative research method as HIV/AIDS-related stigmatization and shame itself is a sensitive issue and is assumed more sensitive when it is linked up with the stigmatized behaviour and lifestyle of people living with HIV/AIDS. As the issue is more concerned with the meaning and quality rather than measurements, the qualitative method has been used to present an interpretative analysis on the representation of stigma and shame towards PLWHA.

3.2.2 Target Population

The target population for the research was people living with HIV/AIDS for which those interviewed constituted the main unit of discussion. Information was also obtained from the local congregation leaders (pastors) and members of the local congregation relating to the congregation role towards people living with HIV/AIDS in Effiduase.

3.2.3 Sample Size and sampling Techniques

An ethical clearance was issued to me by NSD in accordance with data protection legislation (the General Data Protection Regulation and Personal Data Act in Norway). For people living with HIV/AIDS respondents, convenient sampling was adopted in collaboration with the local congregation under voluntary participation. This approach was considered appropriate because the target group was a rare population that was difficult to reach and to interview. The sample size was 12 respondents with the reason of making the outcome representative of the interview. The respondents for the interview were; 6 people living with HIV/AIDS with 3 female and 3 male, 2 local congregation leaders and 4 members who are part of the local congregation. These respondents were found through the collaboration of the local head pastors and two research assistants who were part of the interview process and also members of the congregation.

3.2.4 Sources of data

Information from both primary and secondary sources was collected relating to stigma and shame and the role of the local church towards people living with HIV/AIDS. The primary data was collected with the use of interview guide for PLWHA in the local congregation, the local congregation leaders and some members of the congregation.

Secondary data relevant to the research were collected from different source of books, website, and publications from Ghana AIDS Commission, Ghana Statistical Service, articles and journals which provided a lot of information on literature review.

3.2.5 Methods and instrument for data collection

The study was conducted with the use of qualitative method for collecting data and interview guide. Qualitative method was adopted to obtain in-depth information of stigma and shame in HIV/AIDS, the role of the local church towards PLWHA. According to Flick et al. (2004), qualitative research describes phenomena "from the point of view of people who participate to contribute to a better understanding of social realities and to draw attention to processes, meaning patterns and structural features". I sought to understand the life experience of people living with HIV disease from their own perspective in terms of their relationship and experience with the local congregation in relation to stigma and shame. I adopted qualitative method to enable me to analyse the role plays by the local church in terms of showing care

and empowering those living with the disease in overcoming the stigma and shame associated with PLWHA.

Interview guide was used to solicit information from the respondents. An interview according to Berg (2006) 'is a conversation with a purpose'. The purpose of an interview is to access information. According to Banner (2010), there are three different types of interview; structured, semi-structured and un-structured interview. Structured interviews deal with the use of prepared questionnaires with the researcher focusing mainly to the topic guide which has a predetermined response or answers (Banner2010). Unstructured interviews deal with conversations, where the interviewer and respondent know the topic with no set responses (Baumbusch 2010). I considered the use of semi-structured interviews which are found in between as advantageous in that, it allows the researcher to identify broad themes which will guide the interview process while at the same time preserving flexibility in the pursuit of interesting leads and descriptions (Charmaz 2006). The interview was conducted by separating PLWHAs from other respondents due to the sensitivity of the topic. The PLWHA were further divided into two; 3 female and 3 male were interviewed differently to give fair information from gender perspective. The local church pastors and the members of the congregation were also interviewed separate from the respondents living with HIV/AIDS.

3.3 Research Assistants

I was led to the research area with two assistants who were employed to carry out the local language interpretation and to also guide me to the local congregation leaders (pastors) in the community, who also led me to the local members of the church and PLWHA in the local congregations. These assistants are part of the local congregation that engages in evangelism. It became easy to work with these two assistants because they were well known to the respondents due to their evangelism and activities in their church. Through their evangelism that brought some of the people living with HIV into the church.

Furthermore, these research assistants were native of the community as well as professionally trained teachers. The research assistants were very helpful in the data collection process. The respondents initially were not ready to cooperate as they had doubt about my intention and the implications of their response to the interview. But the immediate intervention of the two assistants as being part of the local church and their native identification in the region made the respondents to cooperate. The research assistants opted to offer their service to me without any fees which helped to reduce my cost on the research. I

guided the two research assistants on how the process of the research should be conducted. In the conversation process, the research assistants asked questions relating to the interview guide to the respondents in their own local language (Twi) and then translated their responses in English Language with the use of sound recording.

On the first day of the interview, the whole interview guide was discussed. The meaning of each interview guide questions was well clarified and how to go about asking the respondents was agreed to avoid different interpretations and understanding. The research assistants' efforts in some of the interview guide questions helped to speed up the whole exercise.

3.4 Transcription analysis of data

Atkinson (1998) identified two major steps in qualitative data analysis, namely, transcription and interpretation of data in accordance with set objectives of the study. According to Halcomb and Davidson (2006), transcription refers to "the process of reproducing spoken words, such as those from an audio taped interview, into written text". I transcribed the interviews conducted with the respondents in both English language and local language (Twi) word-for-word. Interviews discussions conducted with the respondents in the local language (Twi) were translated and transcribed into English Language with the aim of standardization and easy interpretation with the assistance of my two research assistants. I listened to the sound recording several times in order to avoid any misrepresentation of the respondents. The transcribed data was then categorized into themes; patterns of ideas, concepts, behaviour, key words, interactions and phrase used. These themes emerged naturally in the course of repeated reading of the transcribed text. After the themes had emerged, texts from the various interview transcripts were then collated under the identified themes. Finally, the researcher interpreted the data in relation to the purpose, theory and available literature.

3.5 Ethical consideration

According to Gerrish and Lacey (2010), a research is referred as a scientific base in human activity which is carried out on a range of legislation, guidelines, protocol and methods. Research ethics is that field of inquiring that turns to bring out the challenges involve in ethical issues by adopting guidelines and procedures that will safeguard and protect any harm that could happen in the cause of a research against the respondents and protecting the rights of respondents in the research process (Rogers 2008). To solicit the consent of the respondent is a fundamental of ethical research and the important aspect of this is the quality of

information provided to potential respondents. I provided the respondents with an information sheet containing all information about the research process in a clear manner with a personal explanation to any part of the research process which might sound ambiguous or will demand further meaning. I further gave a consent form to the respondents in their own will to append to it without any enforcement. The respondents had the right or free-will to have discontinued with the research process at any point in time if there was any information in the interview guide or the whole data processing against their beliefs. The respondents were given the platform to access further clarification when necessary while research was ongoing. I was conscious of the fact that respondents are not to be harm or experience pain in the cause of the research process as the ethical principle of non-maleficent implies that no harm should come to respondents (Cormack 2000). I was again, mindful of when to stop or continue the interview depending of the frame mind of the respondents as the interview could bring back unpleasant memory to the respondents. Confidentiality is also important in research study as was pointed out by Polit and Beck (2010). The identity of the respondents is expected to be protected when conducting interviews with the respondents. Throughout the research process, I adhered strictly to the ethics of confidentiality in accordance with data protection legislation (the General Data Protection Regulation and Personal Data Act) NSD, Norway.

3.6 Limitations of the study

In every research study, there are some challenges that are expected to be encountered by the researcher. This study had some challenges that need to be addressed. In the first place the study was limited to Effiduase under Effiduase/Sekyere District only. Inferences made pertain to that study area thus making it difficult to generalize to other parts of the country. Another challenge encountered in this study was that some of the respondents living with the disease were feeling reluctant to respond objectively to some relevant issues during the interview. For example, some of them were unwilling to disclose some of the negative attitudes expressed by the local congregation and the leaders in the church for fear of being victimized. They felt that in order to continue to access the positive contribution from the congregation, it makes it difficult to expose the negativity aspect of the local church and its leaders. This scenario might affect the truthfulness of the responses provided in that respect. Another challenge that were encountered during the research was the difficulty of getting PLWHA with the will to participate in the interview due to the stigma associated with the disease and also the financial challenge that I encountered in order to accomplished the

research. Furthermore, ethical challenges in relation to sensitivity of the theme were a crucial thing to handle during the research process. For instance, the confidentiality issues in relation to my translators during the interview with the respondents has to be handled in such a way that the respondents agreed or gave their consent for the translators to be around the interview board before any interview could take place. Again, the confidentiality issue was being dealt with for the fact that the PLWHA already knew the translators in the local congregation and the translators already had background knowledge about the respondents' HIV-positive status during their evangelism which brought the respondents living with the disease into the local church.

Chapter four

4.0 Introduction

This part of the research looks at 'fear' as the main causes of stigma in relation to knowledge and understanding of HIV/AIDS and fear of the disease transmission through non-invasive daily interactions with people living with HIV/AIDS and how these lead to stigma. I will again look at how norms and values of the community influence moral judgement and the impacts of stigma and shame to individual living with the disease. I will also look at the consequences of stigma for the families of people living with HIV/AIDS which I refer as the 'secondary stigma'. This part will also examine the role of the local pastors and the congregation towards PLWHA in the research area. I will further look at how people affected by HIV experience and view the role of the local church. I will again demonstrate the various expressions and forms of stigma which were expressed in the research area.

4.1 Fear as the main cause of stigma

The casual transmission is commonly feared. Some of the people within the research area had the fear that the disease could be transmitted through daily interactions with people living with HIV/AIDS without any exchange of body fluids. For instance, the perception that one could be infected with the disease through mere touch (kiss on the cheek, shaking hands, sitting next to); eating food prepared by or having contact with a person infected with HIV/AIDS; breathing air which has been infected or using items that has been used by infected person or being touched (example bedding, clothing or eating utensils). These were some of the expressions from the respondents in the research area;

“The disease HIV/AIDS might be transmitted through breathing, we do not know. So be caution when you are in the midst of affected people in the congregation is very necessary: staying away from food coming from the affected people during social gathering and not drinking water from the same glass as used by the affected person of the disease.”

People are also afraid whenever he (HIV patient) cooks.... they also fear sharing things during meals. The family is so fearful. Of course, the family does love him, but... (Respondent of a wife whose husband is affected by HIV/AIDS)

“I was part of the usher group in the congregation but unfortunately, some members felt that I could transmit the disease to them so they always try to distance themselves from me.” (HIV/AIDS respondent)

Fear of and preoccupation with transmission through everyday casual contact leads directly to stigma in the form of isolation of persons living with HIV/AIDS in all aspects of daily life. It occurs everywhere, from within the home, to social gathering places in the neighbourhood, to health facilities, the market place, and even places of worship. These illustration show how fear of a wide range of casual transmission situations leads directly to stigma. Even though, there has been a massive awareness in recent time on transmission and prevention of the disease through educational campaign and respondents know, or at least where able to easily recite, the three main modes of HIV transmission: blood transfusion, sex, and mother-to-child, true knowledge does sometimes coexist with incorrect beliefs about transmission, and there is often a lack of confidence about how HIV is not transmitted. The doubts and concerns that exist despite “knowing” that HIV is only transmitted in three ways is described by a health worker in the congregation who was part of the respondents during the research:

“I am a health professional; I am aware that HIV is infected only in three main ways. But when I come into contact with people affected by the disease, I still worry and feel nervous. ... In my case it is my duty to work with them. But in fact I am fearful.”

This attitude from some of the people in the research area could also be attributed to the cultural environment at the place. Majority of the people in the community have associated themselves with certain cultural beliefs that influence their thought and perception about HIV disease and those living with the disease. The likelihood to associate HIV and morality might be related to the fact that affliction is often perceived as an outward manifestation of a moral transgression. According to the respondents from the research area, particular illnesses or

forms of symptoms are connected with having broken one or more social prohibitions. In the community, certain sickness and diseases are considered to be a curse from God which means that the affected person may have committed a wrongful act for such kind of sickness to befall on him or her. They have the belief that by having physical contact with such people can lead to one being infected by such sickness or disease. It is therefore, difficult for some people within the community to differentiate between HIV-related sicknesses and those kind of sicknesses attributed to the gods of the land as punishment or curse as such illness are no different from the symptoms of HIV/AIDS at the peak of it. Most of the people in the community relate the 'peak' stage of HIV/AIDS to mean a curse sickness. According to some of the people living with the disease, this attitude has let the community and some family members to withdraw much attention from them making them to live in isolation without proper care.

4.2 The role of norms, moral judgement and values

The moral aspect of stigma and shame are well known and can be traced back to the original meaning of the word itself, which according to Goffman relates to "bodily signs designated to expose something unusual and bad about the moral status of the signifier" (Goffman 1963). Like the fears associated with the spread of HIV/AIDS emphasised in the previous section, assumptions made about the moral integrity of people affected by HIV/AIDS were a key cause of shame and stigma in the research area, and these assumptions underpin the likelihood to blame people for their HIV/AIDS infection as well as the shame felt at some point which could be link to those affected by HIV/AIDS and those who are closely related to them.

The likelihood to link certain sickness with moral impropriety is a key contributing factor to HIV/AIDS-related stigma. The shame and stigma are exacerbated by the degree of the illness, its mysterious nature, and its connection with behaviours that are either socially prohibited or socially sensitive such as prostitution, sex and drug use. Another important aspect is the perception that HIV infection is the outcome of personal choice: that one chooses to engage in "immoral" behaviours that put one at risk and therefore it is "one's own fault" if HIV/AIDS ensues. A respondent from the research area for example, explained:

"Those who go out of God's permission will be infected. I always advise my children to be loyal to God and respect his rules. Thus, I won't bother if they choose not to be loyal to God and die of the disease"

Another respondent made this statement from the research area: *“...HIV/AIDS is like Sodom and Gomorrah—an abomination of God... it is chastisement. In the Bible says that “What a person sows so shall he reap.”*

In the community where I conducted the research, most of the people also have the same kind of sentiment but framed in a different terms. Instead of the explicit religious references, the community members perceived people affected by HIV/AIDS to have acquired the disease out of lack of self-discipline by engaging in “social vices.” According to some of the respondents, the community members in the research area value discipline and personal integrity and perceive it as the hallmark of the community. Lack of discipline, seriousness, and personal integrity contravenes many of the core value of the community where I conducted the research.

4.3 Shame, blame, and the role of gender

According to the local church counsellor who was part of the respondents at the research area explained:

“.....my experience in this community is that, if men are still young and they indulge in sex and get infected by HIV, that’s the normal story of society. If a girl is infected by this disease, no one would like to get close to her, because it is a problem of her conduct and her morality. It is not acceptable or tolerated in females compared to males.”

In Ghana, more women than men are living with HIV (GAC, 2018). Findings in the research area indicated that women tend to be both more heavily stigmatized than men and blamed more often for “bringing” HIV into marriage or a family. Although, some people in the research area are sympathetic to women who are affected by HIV/AIDS for circumstances beyond their control, women are nevertheless more likely to be viewed as the source of HIV and blamed (Banteyerga, Kidanu et al. 2004). As a woman respondent explained, *“Women would be blamed more than men for being sexually promiscuous and contracting the HIV virus.”* Similarly, a man from the respondents also made the following comment:

“A man would be accorded with more respect than a woman because he is a man. And if a man gets infected, it will be said, “He had HIV infection by accidentally.” But if the woman gets infected, the gossip about her will be more exaggerated. People say she brought the disease by going out with different men.”

Another remark was made by a woman affected by HIV/AIDS in the research area, who observed that *“the word ‘disgrace’ is used more on women.....people say women are the ones who start the illness.”*

A female respondent explained that she was infected with the virus after her marriage to her husband who lives outside the country. After the husband passed away, the entire community pointed at her as being the one who infected her late husband. She faced pronounced maltreatment from her in law’s house after the death of her husband. Even her mother in law claimed, her misdeed is responsible for the virus. The scenario of women is the same in most part of Ghana because women have less access to education, empowerment and decision making right. It has been found that, most of the married women have been infected with the virus by their husbands. Whether or not a woman is blamed for “carrying” HIV virus into a home, the impact of HIV/AIDS-related stigma in the study area was most profound for women.

4.4 Impacts of stigma and shame for individuals living with HIV/AIDS

HIV/AIDS and its related stigma and shame have vast range of consequences for most people who are directly affected by the disease. At the research area, I found a remarkable degree of consistency in the nature of these consequences among some of the people living with the disease,

Given the huge impact a disclosed HIV/AIDS diagnosis can have on the life of an individual living with the disease as a result of stigma and shame, it does not come as a surprise when few people choose to be tested for HIV, and those who get the courage to be tested and it is proven that they are HIV positive, try to do all the possible means to avoid or prevent their HIV status from becoming known to the public especially people living around them.

This section gives an account of some of the more important consequences of stigma and shame for people living with HIV and AIDS in the study area.

4.4.1 Loss of livelihood

Some of the people living with HIV/AIDS in the study area reported one of the most profound consequences of stigma was the impact it had on their ability to earn a living. Some of the People in formal sector employment found themselves being dismissed upon disclosure of their HIV status either voluntary or not, and those selling cooked food or goods found their

customers to be reducing as the day goes by especially when they began to exhibit the symptoms of the disease. These are some of the quotes from the respondents in the research area:

...if the person is seems to be sick and she is selling at the market, people will not buy her stuffs especially if what she is selling is cooked food. (woman from the research area)

...I was working as a department head in a private transport corporation. Many drivers got HIV in that transport organization...and when they got sick they were sacked. (man from the research area as part of respondents)

4.4.2 Challenges of marriage and childbearing

Another consequence of HIV/AIDS-related stigma relates to marriage and having child/children as was reported by some of the respondents at the research area. Marriage couples particularly wives were mostly deserted and isolated after reviewing their HIV status. In most cases, attribution of blames was often associated with this desertion; the first person to become tested among the married couple being considered as the one contracted the disease into the family by being unfaithful in the relationship.

Some of the people who have tested HIV positive from the research area and are unmarried find marriage as no option or available for them. One of the respondents affected by the disease said *“Everyone wish of having a blissful marriage....but because I have got the disease, I do not want to get marry, because if I get married, I would make my partner unhappy, and I won't be happy about that.”*

Similarly, some of the people affected by the disease in the research area in their response to the research interview reviewed that they are not encourage by relative to having children. During the research process, one of the respondents who is affected by HIV says; *“my family may penalized me if I bear children against their advice.”*

Even though, recent development on the knowledge and improvement of antiretroviral drugs for people living with HIV/AIDS which are able to help women affected by HIV to deliver safely without passing out the infection to the new born baby, the cultural setting of the research area in relation to how the family and the entire community perceive PLWHA, this has denied some of PLWHA with the desire to marry and have children not to have the

opportunity to do so with the view that they will infect their partners as well as the unborn child with the disease.

4.4.3 Poor care system towards people living with HIV/AIDS

Some of the health care centres in the research area were reported by some of the respondents to be providing poor service to people living with HIV/AIDS. The consequence of stigma is that, some of the people living with HIV do not get proper care. For instance, a respondent living with HIV/AIDS recounted the following experience at a private clinic: *“I went to a dentist... and told him I am HIV positive. When she heard this, she told me that he cannot help me and asked me to leave his clinic.”*

The impacts of the disease to PLWHA extend beyond the health facilities available to care for them to the health providers and the service at their disposal.

4.4.4 Problem with care giving in the home

According to some of the respondents, health care provision in the research area suffers from various medical constraints, and little can be done within the formal health sector for many of the people living with HIV/AIDS. Due to that, the major part of the care for PLWHA is given within the context of the household, mostly by family members of people affected by the disease and most often by a woman. However, HIV/AIDS-related stigma can result in the refusal of family members to provide this care—whether out of fear of transmission, out of anger, judgment and moral condemnation, fear of experiencing the stigma of others, or a combination of these factors. The impact of poverty and resource constraints at the research area has also contributed a significant limitation of the amount of care any family will be able or willing to provide to someone who is living with the disease. Additional factor is the exhausting often experienced by caregivers, especially as the disease advances and the burden of care becomes increasingly demanding. The following quotes from the respondents at the research area demonstrated this trend:

She was seriously ill and asked her brother to send her to hospital. He refused by telling her that she was hopeless in life. He told her not to bother people and he does not want to waste money on her. (One of the respondents from the research area)

Although, many families love their family members who are living with the disease according to the report from the study, they still distance themselves from the affected person due to

fear. They prefer to find someone who might be living with the disease to provide care for the affected person at the peak stage of the disease, but will not advance to provide care directly by themselves. (A respondents from the research area)

Despite these forms of reactions reported at the research area, however, and despite the prevailing stigma, it was found that the vast majority of people living with the disease did in fact receive loving care in the context of their families.

4.4.5 Internalized stigma

A consequence of internalized stigma can be profound depression. According to some of the respondents at the research area, after the receipt of their status as being HIV positive, and even before any symptoms is shown, they may discontinue employment, and may choose to isolate themselves from their communities and families. This self-imposed isolation can be a product of the shame they are feeling, and out of fear of further spreading the virus through casual contact. As one of the respondents man in the research area explained:

“I do not want to have close contact with people because I know that I am HIV positive.... I am the one who should isolate myself from others. Some of the people who are close to me want to have a good relationship with me, but I do not want to be close to them.”

4.5 The impacts of stigma and shame for the families of people living with HIV/AIDS

The impacts of HIV/AIDS-related stigma do not begin and end with the affected person, but extend to include their children, families, and even caregivers and friends. This phenomenon is mostly referred to as stigma by association or “secondary stigma,”. Because of this attribution of blame, as well as the close shared physical proximity, family members of people affected by HIV/AIDS experience many of the same expressions of stigma as do the those living with the disease themselves, including being the subject of gossip, being socially ostracized and isolated, and even losing employment, income, or housing.

4.5.1 Loss of reputation

The family can hardly be separated from the attitude and behaviour of its children. The family is closely tied to the behaviour of its children. Thus, when someone is known to be HIV-positive, it can reflect poorly on the family, who can lose respect of the community as a result.

“... an infected person is seen as prostitute, a promiscuous person. So when an elder wants to be praised for bringing up his family well, the praise he receives should not be that he brought up prostitutes.” (A respondent living with HIV/AIDS in the research area)

The impact of losing one's reputation in the community can be the withdrawal of vital forms of economic and social support, thus further expediting a family's potential descent into destitution or poverty.

4.5.2 Challenges at work

Upon several challenges that some of the people living with the disease experienced as a result of the stigma and shame often associated with it, these challenges normally extend to some of their family members in the community. Some of the people affected by the disease in the research area reported loss of livelihood in their job places. This situation does not occurred or being experienced by them alone but rather, extend to their family. For instance, a woman in the research area who is affected by HIV/AIDS explained that:

“.....my mother used to take in neighbourhood children as a day care provider. Unfortunately, when it became known to the neighbours about my HIV status, suddenly, the narrative of my mother changed and she became the subject of gossip, all the children were withdrawn from her care, and she had to seek alternative employment which is far less lucrative to make ends meet.”

Sometimes, a family member has to disengaged with his or her work in order to render a full time support to the person affected by the disease when the HIV reach to the peak of its symptoms which makes the patient incapable of doing anything.

4.5.3 Living in isolation

Another occurring experience of family members whose member has been infected by HIV/AIDS is constant living in isolation or being stigmatised at work workplace, public gathering, at schools and even religious gathering. The family members are being tag as easily prone to having the disease or possibly carrying the virus and therefore being left in isolation at any gathering. One respondent at the research area explained:

“My daughter always comes home from school crying.....when it became known to some of the neighbouring that I carry the disease. This information was carried to my daughter's school by the neighbours' children and my daughter has since then been tag negatively.”

4.6 Forms of stigma being expressed daily

The forms of stigma as identified in the research area can be grouped into five broad, loosely defined groups: physical, internal, social, verbal and institutional. I focus in this section on the forms of stigma that are directly experienced by people living with HIV/AIDS themselves, noting where there are particular gender differentials. However, many of the forms of stigma described below are also experienced by people closely associated with those living with HIV/AIDS, like family; including children and other caregivers. The forms and degree of stigma also change over the course of an infected person's experience with HIV/AIDS.

4.6.1 The physical stigma

The forms of physical stigma can be grouped into violent and isolation, with isolation being widespread and the violent less common. Physical isolation of people living with HIV/AIDS occurs in all places, from the home to public spaces like markets, tea shops, buses, sports grounds, places of worship or community gathering, to within schools, workplaces and hospitals. Common expressions within the home include marking and separating out typically shared objects like clothes, eating utensils, and bed linens and making those with HIV/AIDS sleep in separate quarters and eat alone, highly unusual actions in the research area where eating together is the norm with very limited space where family members happens to sleep together.

Expressions in public spaces include not sitting next to or moving away from a person with HIV in public transport, in places of worship, while waiting in a queue or on a bench, or at a tea shop or bar. As one of the respondent explained.... *“No one would sit next to you in the congregation, in the public transport...maybe you cough and everybody has their eyes on you.”* In places where eating together from a shared platter, sharing a communal drinking container, or even sharing washed cups (e.g., tea shops) is common, people living with HIV and AIDS may be publicly excluded, or the usual customs visibly altered when an infected person is present. For example, suddenly individual plates or spoons and forks appear, where eating with hands from a common platter is the norm. Some actions may be very subtle, but clearly recognizable to all as being out of the ordinary. As recounted by one of the respondent living with HIV in the local congregation: *“I asked, Please give me a cup of juice drink” and the server said: “If you drink in the cup, other persons will see you drink from that cup and they won't dare to use it. So take the drink in a plastic bag.”*

4.6.2 Internal stigma

It is obvious that many people affected by HIV/AIDS go through a process, from the initial feelings of shock, despair, shame, and grief. Sometimes it is being accompanied by denial—to (particularly if well supported) an eventual acceptance and understanding that there remains much to live for. The internalization of the stigmatizing attitudes of one's own moral community, often at their worst during the early stages, can remain with one throughout life. While there are a great many expressions of internalized stigma, those observed commonly across the study area included:

- **Loss of hope:** *“I am in such a state—how could I get married? If I could start my life again, nothing would make me happier. As it is, I cannot marry a wife, my economic situation cannot be regained, and my entire body system is not healthy.”*
(Response from a man affected by HIV/AIDS, at the research area).
- **Feelings of worthlessness and with no future:** *“So thereafter I decided it is not worth coming to church. Why go to church when I am already infected with HIV which is not any fault of mine? Why God allowing such a disease to come to me?”*
(woman affected by HIV/AIDS, at the research area)

As the above quotes suggest, a consequence of internalized stigma can be profound depression. Upon receipt of a positive test result, and often before any symptoms appear, people may discontinue coming to church, stop from employment or dropping out of school, and or may choose to isolate themselves from their families and communities. This self-imposed isolation can be a product of the shame they are feeling, and/or out of fear of further spreading the virus through casual contact. As one of the participant explained:

“I am afraid of giving my disease to my family members—especially my youngest sister who is so small. It would be so sad if she got the disease. I am aware that I have the disease so I do not touch her—I talk with her only. I don't hold her in my arms now.”

Ultimately, HIV/AIDS-related stigma results in a loss to families and the local congregation of the distinct and valuable contributions of people living with HIV and AIDS.

4.6.3 Social stigma

The exhibition of social stigmatization can be categorized into loss of identity and role and social isolation. Isolation occurs in various forms both in connection to important family gathering, congregational activities, community events and daily life activities. It takes the

very visible form of the disappearance of invitations to important family gathering and community events such as weddings, or forcefully orders to stay away. One of the respondent living with the disease described her experience: *‘I have a difficulty with my family, particularly my dad. He does not want me to engage in any sort of social life.....He always tells me, ‘Please do not show up closely to our relatives.’ I think he says this for the sake of his family reputation.’* Perhaps a less palpable, but equally damaging expression of social stigma is when people living with HIV/AIDS are no more ask to involve in the planning and hosting of events in the congregation.

4.6.4 Verbal stigma

This is another form of stigma against people living with HIV/AIDS. This can be in the form of direct form such as insulting, pointing fingers, taunting, or blaming, or more indirect form such as gossip and rumours. Gossip and rumours focus on speculation about whether a person has HIV, usually because of visible signs, illness, behaviour, or association with groups seen as “high risk.” Once a person is assumed to be HIV-positive, people often speculate about how he or she contracted the disease. Gossip was shown to be one of the most significant forms of stigma, particularly for women in the research area and in the local congregation. For instance, one of the respondents from the study area living with the disease made this assertion: “let me tell you from my experience. In our local community, I am the only woman who is suspected for having the HIV/AIDS disease. However, many men are suspected and are known for having the HIV virus. But nobody seems concerned and talks about the men. They spread gossip about me”.

More direct forms of verbal stigma were expressed through mocking, taunting, insulting, cursing, and threatening those living with HIV/AIDS. They also included the expression of blame and shame, often through scolding or judgmental statements indicating people with HIV/AIDS “had what they deserved.” People living with HIV/AIDS are blamed for becoming infected with HIV/AIDS through their selfish and irresponsible behaviour, and for bringing shame to themselves, their families and the community as well as becoming a burden to the family. An integral and hurtful expression of the verbal stigma is the use of demeaning and derogatory, pessimistic or despairing language to label people affected by HIV/AIDS.

4.6.5 Institutional stigma

Institutional stigma refers here to differential treatment within any broadly defined institutional setting that leads to a negative outcome for the person living with HIV/AIDS. The main areas documented in the study had to do with loss of or inability to secure livelihoods, housing, health care, and education. It also includes losing access to new or future opportunities because an HIV test is required to qualify for a job, loan, scholarship, or visa for travel; differential treatment within an institution that leads to poorer outcomes (for example having to wait longer for health services); and the way those with HIV are depicted in the media. Not only do all of these forms of stigma lead to reduced life chances for people living with HIV/AIDS, but they also often serve to visibly mark a person as having HIV, exposing him or her to all the other forms of stigma discussed above.

4.7 The role of the church leaders (local pastors) and the local congregation towards people living with HIV/AIDS

In this section, I will look at the role of the local pastor(s) or the church leaders at the research area towards people living with HIV/AIDS in the congregation. I will again examine the local congregational members in terms of the specific roles they play towards people living with the disease. I will look at the positive and the negative aspects that the local church leaders and the congregation perform towards people living with HIV/AIDS. The main reason for evaluating the role of the local congregation towards people living with HIV is to help reduce if not eradicates the stigma and shame attached to people affected by HIV/AIDS. HIV/AIDS is considered to be a disease that can be managed according to recent research as a result of improved antiretroviral drugs, education on its prevention and transmission. But the biggest challenge is overcoming the stigma and shame associated with the disease.

4.7.1 The role of the church leaders

In this section, I will focus on the role that the church leaders (local pastors) in the local congregation play in mitigating the stigma and shame associated to most of the people affected by HIV/AIDS in the research area.

4.7.1.1 Pastoral counselling and spiritual support

In many cases in Africa, some of the people living with HIV/AIDS are afraid of going to the hospital out of fear of the test result. Some of the PLWHA go to see 'local diviners' for treatment and end up with little help. Yet others do not go to hospital and think that their disease is a result of displeasure of departed parent(s) or ancestor(s). The idea that they are sick as a consequence of sin leads to shame and therefore exclude themselves from the fellowship of believers. Pastoral counselling and spiritual support becomes a vital role in this kind of situation for its members who are affected by HIV/AIDS.

According to Koenig, (2008) Spirituality is perceived as meaning and purpose in life, inner peace and comfort, connection with others, support, feelings of love or happiness, and other items. Spirituality and religion play an important role in people living with HIV/AIDS. Spirituality includes the internal, personal and emotional expression of the sacred and is often assessed by spiritual well-being, peace derived from faith, and spiritual coping (Cotton, et al., 2012). Spirituality in people living with HIV/AIDS has been refined as a multidimensional phenomenon which improves quality of life directly and through mediating factors such as church support, optimism and social support. Spirituality helps people to cope with stress, particularly stigma and shame. Understanding a person's spiritual grounding is important to understanding how someone deals with illness, treatment, death and bereavement. Addressing the spiritual needs of PLWHA helps to empower them and facilitate quality treatment geared towards specific needs and desire.

According to the local pastor of the Methodist church in the research area, the church has created HIV/AIDS counselling unit with its numerous functions, advocate for the knowledge of HIV in terms of its transmission and prevention, encourage members within the congregation to go for voluntary testing especially prospective marriage couple when the need arise. For instance, the local pastor explained: *".....through this counselling, two couple decided to get married but later decided to go their separate ways when one was tested HIV positive. They had a consensus decision not to marry in a peaceful manner."*

Another respondent affected by the disease explained her experience: *".....I was counselled under this unit and I came to appreciate the fact that in my prayer of seeking God's help and protection due to my sickness, I should not forget to constantly go in for antiretroviral drugs from the hospital."*

Pastoral counselling is a crucial element which the church provides for the restoration of people living with HIV/AIDS. The people living with HIV/AIDS need reassurance, encouragement and acceptance from the church. Pastoral care or counselling is a designed process to care, cure and support a person in order to restore his or her wellbeing due to sickness, challenges or loss of hope. According to Benner (2006), the aim of counselling is to help the person who is going through a difficult situation to find solution to his or her situation. According to the local pastor of the church, the church have created a counselling unit which play a vital role of giving pastoral counselling for members who have been infected by HIV/AIDS. Among many challenges that PLWHA face as was said by the local pastor, shame and guilt are part of it that need to be addressed in order to help them to reintegrate well in the community. People living with HIV/AIDS should be able to attain and restore their dignity and self-value that was embedded in them during creation.

According to the local pastor, the need to proclaim the hospitality of God to the understanding of people living with HIV/AIDS is very crucial. This according to him is one way of breaking the vicious cycle of stigmatization. The local pastor reiterated that, the commandment to love should be interpreted in such a manner that cares for the person in need is more important than the law and judgement of the affected person even if the person has acted immorally.

The key role played by the Bible in Ghana and Africa in general has major implications for the church's response to HIV and AIDS. According to the local pastor, he explained: *“the Bible was often read in such a manner that did not affirm life. Many Christians turned to passages like ‘for the wages of sin is death’ (Rom. 6:23) to account for the suffering and death of people living with HIV/AIDS.”* The pastor further explained that in the Bible context which says that God rewards good people and punished evil in most of the time have generated stigma toward people living with HIV/AIDS. According to the pastor, he used the pulpit as an opportunity to diffused the negative impression in the minds of congregational members and to those living with the disease about these Bible texts and to bring members understanding about God's love, care and compassion for all including the sick, vulnerable in society and marginalized members of the community.

Notwithstanding the actions taken by the local pastors and the congregation to mitigate the stigma and shame associated with HIV and AIDS-related disease, some of the respondents living with the disease felt that the local pastors or leaders are not performing to the

maximum expectation in relation to PLWHA. Some of the respondents believed that the local pastors under-used the pulpit to disseminate information and educate members properly on how to curb the stigma and how members could relate well among PLWHA. There is much gap in what is being said by the pastors and what is actually being practice according to the word preached. For instance, one respondent explained that: *“.....our pastors always admonish that congregational members should always do their best to interact, show love and make visitation to PLWHA even in their worse condition. PLWHA should always be welcome when they also reciprocate visitation to any of the congregational members. But unfortunately, the local pastors hardly make such visitation to PLWHA”*

Another respondent explained that: *‘I last time made a visit to the local pastor and unfortunately, I could not have the opportunity to interact with his family even though they were available. Even on my request to talk with them, I was told there is no need to see them’*

These quotes from the respondents mentioned above, shows that the local pastors merely used the pulpit as a formality of delivery the gospel message but without or little actions from what they say to the congregation to do. This gives doubt in the minds of PLWHA about the seriousness of the message that come from the local pastors to the congregation. As was said in the Bible (James 1:22-25), *“But be doers of the word, and not hearers only, deceiving your own selves. For if any be a hearer of the word, and not a doer, he is like unto a man beholding his natural face in a glass.....”* The pastors can set themselves as exemplary leaders by first demonstrating to the congregation on how to accommodate PLWHA and help to reduce the stigma and shame associated with PLWHA.

4.8 The role of the local congregation

According to the local congregation at the research area, they have not relents their effort in relation to their role towards people living with HIV/AIDS. Members in the congregation have engaged themselves in various fellowship groups with the aim of winning soul for Christ and supporting members who need support, care and love especially PLWHA.

According to the report from the research area, the local church have put an effective response to PLWHA which in most cases were not documented as they based their reasons from the Bible texts which explained that one does not need to let the world know the good things one does to his or her brother as found in (Matt. 6:1-4) *‘Do not do good things so that*

people will see you do them. If you do, you will get no reward from your father in heaven.....but when you give money to poor people, do not let your left hand know what your right hand is doing. In this way what you give to the poor will be secret. Your father sees secret things and will reward you.’’

The teaching of the church on giving without expecting anything in return has proved to be more effective than organizations that attempt to attract people by promising material rewards. The church women’s fellowship is especially significant in the provision of voluntary work. These women from the congregation answered the call to serve the marginalized, vulnerable and the poorest of the poor. They often cook and bathe the sick affected by the disease who are members of the congregation.

According to the local pastor, the local congregation have provided free services to the most vulnerable social groups especially orphan children whose parents died of HIV/AIDS, people living with HIV/AIDS, widows among members in the congregation and the community in a form of their basic material needs, financial support which were basically not documented. Some of the congregational members have put themselves together to give a caring and compassionate face towards people living with HIV/AIDS through visitation as one of their priority to those affected with HIV-related disease in their various homes by praying with them and giving them hope through Christ ministry. The church provides some support for those who have lost their jobs as a result of the disease and also provide financial support to orphans who have lost their parents through HIV-related disease.

The church members in their often visitation to the sick, orphans from members who passed on with HIV/AIDS and constantly engaging in prayer with the affected members in order to restore their hope, it was noticed that some of the families of those with AIDS will be widowed and orphaned. Most people living with HIV/AIDS experience alienation and are often face with stigma, discrimination and isolation. As was reported from the research area, some of the families with a member dying of HIV/AIDS are largely left to its own devices, the community preferring not to get involved. This is far from being outside of God’s concern. People living with HIV/AIDS are among those to whom the Bible calls the people of God to minister. Instead of thinking of PLWHA as people being punished for their sin, the local congregation at the research area are being encouraged to accept PLWHA as one of their own through crusade by developing ethical outlook among Christian and the community

to enable people to avoid life-threatening behaviour which will encourage people to show love and care for those living with HIV/AIDS.

According to the respondents from the research area, the local congregation with its various organizations like women fellowship, men fellowship and youth fellowship have embarked on numerous activities in collaboration with other FBO and religious bodies in the region on educational campaign in the spread and prevention of the disease, providing healthcare in a form of antiviral drugs and demystifying the stigma and shame attached to the disease which are not documented.

The church has adopted the biblical teaching beyond sexual behaviour to include grace and forgiveness, compassion and solidarity in suffering. A theology about HIV/AIDS must always take into account and uphold God's involvement in the world and concern for the poor and unprotected. The church in their role to reduce stigma and shame linked to people living with HIV/AIDS, whose lives in most cases have been made miserable and desperate by the disease is using the ministry of Christ to integrate these people to fellowship together by showing hospitality, love and consideration towards PLWHA and making members to understand that the disease is not sent by God as a punishment for sexual promiscuity as it has been misconstrued by many members in the congregation. For instance, Jesus Christ in his ministry said *“come to me, all you who are struggling hard and carrying heavy load and I will give you rest. Put on my yoke and learn from me. I am gentle and humble and you will find rest for yourselves”* (Mathew 11:28-30). The local church and its leaders make Jesus Christ a centre stage for all members especially those suffering from the disease.

The Methodist Church at Effiduase as part of their social responsibility to the community has built a clinic as additional support to the government hospital in the region. The clinic has been designated to provide healthcare to the members in the church and the community as a whole and also provide antiviral drugs to people living with HIV/AIDS. The local church has made this service to be free for people affected by the disease and this has gone a long way to improve the health situation of PLWHA.

4.9 How people affected by HIV/AIDS experience or perceive themselves

In this section, I will focus on how PLWHA see themselves after contracting the disease. This section will look at their feelings, how they think of others who are not living with the disease and what they assume others think about them.

4.9.1 Internal stigma

The majority of the people living with HIV/AIDS disease suffer from internal stigma as was disclosed by some of the respondents living with the disease. The revelation was that HIV/AIDS is considered to be a moral punishment, and a curse. The main cause of HIV/AIDS is having unprotected sex throughout the world. Some of the people living with HIV/AIDS in the study area try to understand what other people think about them, how the society perceives and make judgement about them. They wanted to judge themselves reflected in other people's attitudes and behaviours toward them and by imaging what people think about them. The society or community view is just like a mirror for some of the people living with the disease. This reflected image sometimes make PLWHA feel very bad and guilty about themselves because they see themselves as rejected by family members, relatives and friends. Some of the people living with the disease in the research area are forced to believe that they carry the virus because they have done something wrong and they deserve it. These negative reactions are mostly linked to unethical sexual intercourse and other activities that are hardly sanctioned such as extra marital sex. A country with majority of the populace being Christians and Muslims, not only sexual promiscuity and extra marital affairs looked down upon; pre-marital sexual relationships are deeply not acceptable.

Majority of people living with HIV/AIDS in the research area feel they have nothing to do for their family. They have disappointed others and have brought bad omen and shame to their family members. Sometimes, they show strong anxieties and fear about infecting others. Some respondents revealed that they are afraid of infecting their family members especially their loved ones and little ones in the family. Some of the people living with the disease think that they are not allowed to share their drinks and foods with others. The results regarding self-perception suggest that more than half of the people living with HIV/AIDS vehemently blamed themselves for their HIV/AIDS status. People who are affected by HIV/AIDS and accept society's negative reaction may feel guilty and blame themselves for the intolerance of others, feeling that they deserve mistreatment (Herek et al., 1998). In extreme cases, this has led to some of them thinking about committing suicide due to their status. One respondent revealed that she was not allowed to engage in meal preparation meant for congregational feast because of her HIV/AIDS status in her previous settlement and she thinks it will be better to die. People affected by HIV/AIDS feel completely hopeless as they think that they are going to die and they have nothing to offer for the society. They believe this disease just as a result of their misdeeds and their existence becomes meaningless.

4.9.2 The attribute spoils the identity

The respondents revealed that their contraction of HIV/AIDS had a negative change in their lives. While a few of them reported physical decline, all the respondents disclosed how HIV/AIDS infection redefined their social life. Key to this is what the respondents regard as the stigmatising individuals' negative definition of the behaviour of PLWHA. Family, friends, the workplace and the society in general tend to view HIV-positive people as filthy, irresponsible and immoral. One respondent reported that:

‘I think they feel that we are filthy people because if you are clean, like a virgin or with one partner in your whole life, then you would not get it. Again, people think we will die soon and therefore they must keep a distance from us because we are angry and may transmit it onto them. That whole thing that went on a few years about pricking people with needles that had HIV blood on it has scared people. They think we are all cruel and angry and wanting to infect others because we are dying. I just know that generally, people will prefer not to deal with us if they know we are HIV positive.’

Another respondent living with the disease experience captures the negative definition of the behaviour of PLWHA by the ‘normals’:

‘People believe that if you have HIV/AIDS then you deserve it because maybe you slept with more than one person. They think you were immature and irresponsible.’

One respondent who gave account of his neighbour who revealed that her husband was HIV-positive:

‘No one visited him. Everyone spoke about him and how sad it was. Some said he deserved it because he was a real player. Others said that if they went to see him, then they could get it as well because they would be in the same room. When he died, few people attended his funeral which was unusual in the community. She has nowhere else to go. People don't talk to her right anymore as well. They like gossip all the time. Once you live with someone who has HIV, people think you have it too.’

A person infected by HIV/AIDS can no longer be given the recognition and respect that the uncontaminated aspects of his/her social identity have led him/her to anticipate receiving. Some of the respondents tend to think that whatever others profess, they do not really accept PLWHA on equal grounds. One respondent living with the virus gave an account of her workplace experiences resonate with this statement:

‘I informed my supervisor that I have been infected by HIV/AIDS and I wanted him to know in case I become sick. But soon all the managers got to know. The managers started giving me lesser work and my colleague staffs started to avoid me.’

However, some of the respondents revealed that they had significant others who were sympathetic to their condition. These were people who played a vital role in the life of the respondents. A female respondent revealed that she sought social support by joining the church counselling to PLWHA:

A female respondent, who concealed her HIV-positive status for a period, finally revealed her status:

‘I trusted my local pastor and family member. They have supported me. But not everyone has the same attitude. I feel that generally, people will be scared of you and will want to stay away. They can get angry at you and say it was my fault I am HIV-positive and I deserve it.’

4.10 How people living with HIV/AIDS perceived the role of the local congregation.

In this section, I will look at how the PLWHA perceived the role of the church towards people affected by HIV/AIDS

The local congregation in its attempt to promote a good relationship between the church and PLWHA, is being surrounded with some negative attitudes which are expressed by some of the members and also common to other religious groups in the country in relation to PLWHA. I will look at some of the negative attitudes being expressed by some of the members in the local church which need to be deal with in order to bridge the gap attached to stigma and shame towards people affected by the disease. I will further examine the positive attitude that have influenced positively on PLWHA in the research area.

The negative notion of categorising people living with HIV/AIDS as sinners, unworthy, adulteries, social outcast etc., by the church ministry and the general public has negatively affected and increase the stigma and shame attached to the disease and thereby making those living with the infection to hide themselves in order to avoid judgement. According to Oyvind M. Eide et al (2013), the church teaches that the consequence of sin is suffering and sometimes death and for that reason, a person suffers because of his/her choices contrary to the will of God. The local congregation see extramarital relationships as sin. Sin breaks our relationship with God. The church is sensitive to sin related to sex. For instance, a man can be

excommunicated for committing adultery but not for beating his wife, stealing or gossiping (Kimilike et al 2013). The church considered matters related to sex as secret and are associated with a sense of shame when exposed to the public. While shame seems to be rooted in cultural traditions in Ghana, judgemental attitudes seem to be rampant in church. Christians teach that the consequence of sin is suffering and sometimes death. A person suffers because he or she has made choices contrary to the will of God. This is understood as a reason for being infected. The church leaders preach that sinners reap what they sow and therefore your sickness could be a result of your bad deed. One respondent explained: *‘Many of the infected seek to repent their guilt but unfortunately the church and the community does not differentiate between who is guilty and who is not.’*

The influence that church leaders or local pastors have in the community allows them to be approached by individuals in times of need. They have the pulpit as a powerful tool for Christian education which allows them to reach out to a large number of their members; the Church is thus an institution that addresses more people consistently, at all levels. In this regard, the pulpit can be used to spread information about HIV/AIDS prevention and care for PLWHA. It appears, however, that the pulpit has been underutilised as far as fighting HIV/AIDS stigma is concerned. Instead of calling for acceptance, forgiveness and love for PLWHA, it has rather been used to reinforce stigma (Chitando, 2007).

Another respondents living with the disease at the research area, explained that: *‘the church as the body of Christ is expected to emulate the exemplary life of Christ. For example, Jesus reached out and healed those whom the society has rejected or considered ‘outcasts’, those considered unclean and stigmatised due to their physical condition, those scorned for the sake of what they do such as adulterers and sex workers.’* According to the respondent, Christ demonstrated how God is and how the church should emulate and extend this treatment to those infected with HIV/AIDS. People affected by the disease perceive this role and attitude from some of the local congregation as disturbing and make them to feel that they do not belong to the church.

Despite these disturbing attitudes from the church, majority of people living with the disease perceived the role of the church as having a significant impact in their health and life. One respondent from the research area expressed his view;

‘My belief in God through my Christian faith from the local church is making me strong. I have medicine from the local clinic but God is helping me. Through prayer with the

congregation, I can talk to someone.....if I was not a Christian I would have killed myself..... When I pray and read the Bible, I get hope to live.’’

The local church in their role of empowering its members through joint prayer has helped to restore hope among some of the people affected by HIV in the research area. The Church in Africa has prayer and spirituality as relevant tools to utilise in the struggle against HIV/AIDS stigma which is useful in creating a sense of courage and strength for PLWHA (Chitando, 2007). If prayer and spirituality become an integral part of church life, it means that the people whom the Church reaches will experience a joyful relationship with God and experience the hope from God. One of the women respondents explained;

‘‘God answers me when I pray....since I joined this local church, my faith and hope in Christ have been strong. Many things I have put before God have always been answered....with this faith I have built after joining this local congregation, I have ask God to make the HIV diagnose disappear and cured and that would be a testimony.’’

Another respondent says: *‘‘I received prayer from my pastor and I know my HIV diagnose will be cured as I have faith in God. My hope in life has been restored again through the counselling that I receive from the pastor’’ (A woman respondent, affected by HIV)*

The material support from the local church to PLWHA at the research area cannot be underestimated as was expressed by one of the respondent; *‘‘I was mostly lonely as my family were not taking care of me properly. The local congregation have been supportive to me.....they support me with foodstuffs and financial support and make regular visitation. I am grateful to God for leading me to this church in my sick situation.*

The quotes cited above from the respondents in the research area gives a brief account on how the PLWHA perceived the role of the church at the research area.

The summary of this chapter leads to the suggestion that church leaders or local pastors having the difficulty of developing an effective religious values and strategies in dealing with stigma and shame towards PLWHA, must be guided according to God’s commands in order to protect PLWHA against stigma and shame. Churches and their leaders in most cases have adopted a theology of judgment that has reinforced stigma and shame against PLWHA. There is the need for a paradigm shift of this thinking in order to adopt a theology of acceptance that accommodates all people as being created in God’s image, despite who they are and what they are going through.

Chapter five

5.0 Introduction

This chapter presents further analysis and discussion of the findings from the interviews. References are made to literature to support and discuss the findings. In order to provide a deeper understanding regarding the context, I will describe how the culture of the study area affects the church's effort in their role towards PLWHA. I will describe how social norms, values and beliefs play role in the community which hinder the empowerment of PLWHA in the study area especially women living with HIV/AIDS.

5.1 Social structure and internal Stigma in relation to Women

Social structure, in this study, refers to the social norms and values, regulatory and socio-economic conditions within which the respondents in the research area experience especially PLWHA. A key similarity responded from the research area was the role that gender plays in relation to HIV/AIDS-related stigma, shame, and blame. It is obvious that women normally bear the strongest brunt of this type of stigma. The reason underlying this seems to be that women in the research area are expected to uphold the moral traditions of the society. HIV/AIDS is regarded as prove that women have failed to fulfil this important social function. To phrase the problem otherwise: Women affected by HIV/AIDS are regarded as everything that they should not be; being cared for when they should be caring for others, sick and slim when they should be healthy;; sexually deviant when they should be sexually righteous. To be HIV-positive is not to be a proper woman (Bond, Chilikwela et al. 2003).

A key double-standard exists in this research area, whereby men are normally expected to be adventuresome, reckless and more likely exposed to all forms of sexually transmitted infections (STIs) including HIV while women are expected to be sexually faithful, and morally upstanding.

The study found that most women in the research area are being denied the right to experience life in their own desire as compare to their male counterpart. Even different perception is shown to men who contract HIV against women who are also affected by the disease. This influence or social structure even has an influence in the church organization. In a study focusing on HIV/AIDS stigma in the African context, Kelly (2002) referred to vulnerability to HIV stigma and shame as connected to existing stereotypes, including poverty, intolerance and inequality between women and men. Kelly's study shows that in

Sub-Saharan Africa, issues of gender as well as poverty, lack of economic opportunities, limited access to education, information as well as traditional norms and practices significantly increase a woman's vulnerability to HIV lie at the root of her experience in trying to cope with the related stigma and discrimination. Their roles in the household and at the community level are on domestic duties and caring for the children. They had little involvement in decisions and felt they had low self-esteem. This has resulted in many women being affected by the disease when the social structure makes them vulnerable.

According to Paxton, within the family, the church and the community, women are significantly more likely to experience personalized stigma than men, including ridicule and harassment, physical assaults and being forced out of their homes (Paxton, 2005). The situation of women is very vulnerable as they encounter greater stigma than men in our society. At the study area, it was found that women are not equally treated with men in the community. HIV-positive women face physical, mental and emotional abuse by their husbands. Most women with HIV may think their identity, status and self-respect have been damaged. They felt shame and guilt and blamed themselves. In some cases, it is reported that female spouses also tend to keep silent even if they are infected by their husbands, as they don't believe they have many options open to them if they were to leave their husbands. However if the husbands are infected by their wives, it was mentioned that many choose to abandon their wives and leave them to manage on their own.

The research area is completely a patriarchal society where all of the organization is male oriented. In Ghana, most women found themselves at the disadvantage group more than male in regards to health facilities, education and economic condition. Women have few opportunity and scope to take their own decision especially for the cases of safe sex practice. Most women are not able to determine when to practice safe sex because of lack of power to control their own lives; they are frequently infected by their husband with HIV virus. They have not enough resources to cope with the situation. Our society expects that women should be involved only for their reproductive activities and household. Although men and women are considered equal under the law, women still face discrimination in certain areas especially in the research area. Well defined gender roles exist in Ghana where women are expected to perform domestic labour without pay rather than work for an income, which limits their independence. Women are more likely to be impoverished, denied education and in danger of exposure to physical violence as the Bible say in (Hosea 4:6) "my people are destroyed for lack of knowledge....." When women are given education, safe homes and care; they are

better equipped to help themselves and their families to prevent poverty, have knowledge on safe sex and reduce or eliminate prostitution and sexual promiscuity which lead to high spread of HIV/AIDS.

5.2 Diaconal identity and care oriented

Diaconal identity and care oriented were fundamental element which the church has incorporated into their doctrine and a vital role of the church towards people living with the disease and to the community in general. When expressing their view of the role of the church towards PLWHA, all respondents emphasized on the need to fight for justice, human rights, and work for PLWHA as most of them have been social outcast due to their ailment and stigma associated with the disease. The key elements in care oriented engaged by the church towards PLWHA are home visit, counseling and spiritual support, financial support, prayer meetings etc. which most respondents admitted that the church in the research area engagement is very encouraging. According to my findings, most respondents place a high value on diakonia. They emphasize hope that diakonia will not only impact the church and its congregation, but that it will contribute to help and heal members within the community with HIV-related disease who have been neglected by the community.

Another aspect of the churches diaconal identity and responsibility that came out during my research was the idea of the church being perceived as a role model in society, as was an ideology that was expressed by some of the respondents.

The role of the church is expressed as a role that sees and tolerates people, gives second chances, a role that looks beyond someone's past. A "role model" could be interpreted to mean different things, but I believe in this aspect the respondents use it to describe practical aspects of diakonia which the church is expected to act towards PLWHA and improve the life of the sick, showing love, compassion and care to the helpless and voiceless in society. One respondent says, "*The church should be doing what Jesus did; he saw people, he cared for people.*" The ultimate role model is Jesus, and the churches role is therefore to represent Him. The church has a role to fight for the people that fall "outside" society, or help the ones that have been rejected by the society. Different examples were given by the respondents in a form of playing advocacy role in mitigating the stigma associated with the disease, providing health care facility, financial support, and assist in antiretroviral drugs by collaborating with other religious bodies which can go a long way to improve their life. The engagement of

PLWHA in job activities will help curb stigma instead of being disengaged from their work without their concert.

5.3 Spiritual dimension as a form of healing

Another dimension that surfaces in my findings was the spiritual dimension and role of the church towards PLWHA. Although all respondents acknowledged that there is a spiritual dimension to their health, the local pastor stressed that the church stuck out as to put extra focus and attention on this aspect. The church of this respondent has a large part of their diaconal work in the form of prayer and prophecy. The respondent uttered the importance of Christians using their spiritual gifts given by God, as well as acting on God's word. For instance, the practice of laying hands on the sick and praying for the sick by the local pastor(s) in the church was a vital aspect in drawing the sick closer to God and also deriving inspiration and hope through such activity. Additionally, the church has a prayer room open for all walks of life including PLWHA on every Wednesday of their church service. In the prayer room, members of the congregation receive prayer upon request, as well as prophetic words. The spiritual dimension from the church is believed to help most of the PLWHA in reducing stress, improving their psyche and above all restoring their hope

The spiritual dimension as a form of healing through faith in God in my observation from the research area could result in the difficulty of fighting the spread and prevention of HIV/AIDS in the society. For instance, in the findings from the study, one female respondent admitted that she has the faith in God that her HIV virus will be cured by the prayer she has received from her local pastor. This belief in faith from the church can impede the struggle about HIV prevention and treatment by creating awareness for people living with HIV/AIDS to patronise antiretroviral drugs which help to improve the life of PLWHA. Instead of the belief in faith from the church transforming the lives of PLWHA, it could in most cases worsen their plight of health because some of them would be discouraged to attend to health clinic for antiretroviral drugs.

Although, the local pastor vehemently emphasised that God can heal all manners of diseases including HIV through prayer, such message is not necessarily intended to mean "without medicine". But it can be misinterpreted by some of the church members. He based on Bible text (Jeremiah 30:17) and the Lord says "*I will give back your health and heal your wounds.*" He further made submission that the church in most cases advice its members

especially PLWHA to combine faith and medicine with the hope of getting heal from their sickness or improvement in their health.

Acceptance and encouragement can be compromised when churches encourage people to pray to be cured and stop taking their antiretroviral (ARVs). Although this is often rare, there are some few minorities of pastors from different denominations who choose to remain vague about healing and HIV and, often accidentally, lead some members of their congregations to stop treatment. Unfortunately there have been cases of people dying from HIV/AIDS after stopping their antiretroviral, believing they will be cured by prayer. This makes it necessary to recognise the need to engage faith leaders of all denominations in discussions about HIV/AIDS prevention and treatments.

I therefore believe that a role model could be viewed as being a representative or spokesperson of God, or an ambassador as written in (2Corinthians 5:20) says; *“We are therefore Christ ambassadors, as though God were making his appeal through us.”*

5.4 The church as a healing community

Relating to the intervention in the area of fighting HIV/AIDS stigma in the Church in Effiduase, it is the local pastors who are mostly concerned, as their involvement means that they can then lead their congregations into action. This means that, if the local pastors are reluctant in fighting against stigma, their congregations will not be involved. On the other hand, if church leaders or pastors stand against stigma, they will be able to motivate their members to join the fight.

In the period of difficulty as experience by people living with HIV/AIDS, church leaders are expected to help the Church to bring healing. The idea that the Church should be a healing centre raised a question as to what healing is about. According to Elwell (2001), —Healing is the restoration of health, the making whole or well whether physically, mentally, or spiritually. This definition elicits an idea of healing as a multidimensional act. Marshall et al. (1996) give a similar definition, but indicated that healing includes recovery brought about by medical treatment or spontaneous remission of sickness. It also includes the improvement in a patient’s outlook, even if there was no physical change, or a correction of the patient’s misconception of the nature of illness. In addition, as Moore (1988) states, in its multiple dimensions, healing is basically about recreating a broken life, and demands the presence of a healer who participates in the healing process. Healing is also a mystery to be celebrated;

therefore need to be regarded in acknowledging and witnessing Christ as the living God, the physician and saviour of all mankind and creation.

Healing as appeared in the Bible can also referred to as showing care. In Ezek. 34:4, the Lord condemns the shepherds of Israel saying, *‘you have not strengthened the weak or healed the sick or bound up the injured.’* This refers to God’s rebuking the leaders of Israel for their inability to look after the people under their care (Carson et al., 1994). In the scripture then, it is found that healing can carry the meaning of spiritual restoration, or the caring for those who are experiencing great suffering

The healing work of Jesus was directed towards all those who had an encounter with Him while suffering. As a summary of the way Jesus intervened in the suffering of the people, Matthew 9:35-36 says, *‘And Jesus went about all the cities and villages, teaching in their synagogues, and preaching the gospel of the kingdom, and healing every sickness and every disease among the people. But when he saw the multitudes, he had compassion on them, because they were harassed and helpless, like sheep without a shepherd.’* In these verses, Jesus works hard for the kingdom of God. He finds Himself among people who are troubled and helpless, and in need of healing. Moved by compassion, He then preaches, teaches, and heals. Compassion is Christ’s motivation to heal. The context of this passage argues that compassion is, after all, a feature of Jesus’ ministry. For that reason, this research study agrees with Carson et al. (1994) who posit that the basis of Jesus’ compassion was more an emotional response resulting in caring action.

The Christian ministry of preaching is grounded in the ministry of Jesus. In His preaching, Jesus proclaimed the kingdom of God and also announced the good news of salvation. The ministry of the word can be used by church leaders to encourage PLWHA and to challenge church members to change their attitudes towards them. For that reason, what can be said here is that through preaching and teaching, members of the congregation are told about how to live a life which is characterised by love for one’s neighbour.

5.5 Social meaning of HIV/AIDS stigma

One of the key of Goffman's stigma theory is that society put people into ‘normal’ and ‘deviants’. This categorization is ideological. The individuals regarded as ‘deviants’ are stigmatised because they are said to be discounted and tainted, possessing an undesired differentness from what the ‘normal’ anticipated. The stigmatising constructs an ideology or

a stigma theory that rationalises the treatment meted out to PLWHA by the ‘normal’. The attribute that they possess disqualifies them from full acceptance by the ‘normal’.

Society associates the presence of the disease agent with negatively defined behaviours. For instance, while HIV/AIDS is associated with homosexuality and intravenous drug users in America, in Ghana, promiscuous heterosexual sex is perceived as the primary mode of transmission. The likelihood to associate HIV and morality might be related to the fact that affliction is often perceived as an outward manifestation of a moral transgression. According to the respondents from the research area, particular illnesses or forms of symptoms are connected with having broken one or more social prohibitions. Attributing stigmatised medical conditions such as HIV/AIDS to lack of personal responsibility has the effect of distancing the ‘moral majority’ from risk (Deacon *et al.* 2005). The strength of the stigma rises when the cause of HIV infection is seen as some avoidable and negative behaviour such as promiscuity or other morally sensitive issues. The reverse is true when the HIV infection is believed to be accidental such as due to blood transfusion. The response in such situation is expected to be pity. However, the fact about HIV infection is that multiple partners and promiscuity may increase the chances of contracting it but it can be contracted by a person with one unfaithful partner (Deacon *et al.* 2005).

People have long been socialised into knowing what it means to be ‘normal’ and to have AIDS or be HIV-positive. Individuals come to know that the society tends to treat those who are living with HIV/AIDS with less respect. This knowledge may make it easier for PLWHA to discover the reality behind the façade that the ‘normals’ profess. As Goffman (1963) said, the stigmatised ‘may perceive, usually quite correctly, that whatever others profess, they do not really ‘accept’ him and are not ready to make contact with him on equal grounds’. The stigmatised can no longer be accorded the dignity, recognition and respect that ‘the uncontaminated aspects of his social identity have led them to anticipate extending, and have led him to anticipate receiving’ (Goffman, 1963). Through stigma the life chances of the stigmatised are reduced. For instance, the career prospects of the stigmatised are curtailed by the differentness or the fact of being HIV-positive. This sentiment is echoed by some of the respondents regarding the diminished chances for promotion or development that they experienced in their workplace.

Central to Goffman's (1963) notion of stigma is the issue of relationships. Stigma is not just an attribute. It should be seen that a language of relationships is needed. Such a language

involves the labelling of a person as deviant or discredited. The negative labelling reaffirms the normalcy of the person doing the labelling. The results of the study authenticate the notion that stigma is a social process that can be enacted by and experienced from family, friends, religious groups, the workplace and the society as a whole.

There are instances when a discrepancy develops between an individual's virtual and actual identity. Actual identity is about the attributes that the person actually possesses whilst virtual identity concerns those that society imputes to the person. When the discrepancy is known about, it may spoil the social identity of the stigmatised. Social identity entails the attributes that the person is thought to possess in relation to others. The effect of stigma is alienation from oneself and society and facing an unwanted world.

In line with Deacon *et al.* (2005), the outcome revealed that when the 'normal' express stigmatising thoughts, even if indirectly, PLWHA tend to experience the moral judgement projected onto them. Some of the respondents expressed the view that the contraction of HIV/AIDS spoiled their identity. The direct and indirect experiences of stigmatising views from the 'normal' may reveal the internalisation of stigma by some of the respondents. In responding to stigma, the individual may self-stigmatise by way of accepting the negative social judgements of their own identity.

Within the social environment of the stigmatised person, Goffman (1963) identified two categories of sympathetic others, namely, the 'own' and the 'wise'. The 'own' are individuals who share the stigma with the stigmatised person. The 'wise' are persons who are 'normal' but whose special situation has made them intimately privy to the secret life of the stigmatised individual and sympathetic with it, and who find themselves accorded a measure of acceptance, a measure of courtesy membership in the clan.

The presence of the 'wise' presents the stigmatised with an accepting environment whereby he or she does not have to feel ashamed in spite of his or her differentness. In this study the 'wise' person are the local pastors or church leaders who had pre-knowledge about members living with the disease and the research assistants who had a good relationship with respondents.

The other type of 'wise' person is the individual who is related through social structure to a stigmatised individual, such as family members like spouse and children of the person living with HIV/AIDS. In fact, stigma can spread from the stigmatised individual to those with close links to him/her as society's tendency is to treat them the same. Some of the respondents

expressed the view that if they revealed their HIV-positive status, the community may victimise their family.

Goffman believed that a stigmatised individual may have experience of both discredited and discreditable stigma. Regarding being discredited, the stigmatised has to manage the tension generated during social contacts and face prejudice against PLWHA, whilst the discreditable has to manage information about his/her failing.

The study has revealed that individuals cope with HIV/AIDS stigma in a different manner. For some individuals, especially the discreditable, non-disclosure of one's status is the best way of managing stigma. However, this non-disclosure is not denial of one's HIV/AIDS status. It entails disclosure to health care providers, and it may not mean non-disclosure to one's sexual partners. On the contrary, it may mean abiding by safer sex practices as in the case of the respondent who informed her partner and the one who preferred not to marry due to her HIV positive status. Some of the PLWHA encounter stigma in the church and the 'normal'. Non-disclosure may denote that they have internalised society's prejudice towards those living with the virus. As a result, some of the respondents relied on social withdrawal and self-isolation to cope. These individuals may not disclose their status because they want to avoid being stigmatised, to have their privacy and peace of mind.

It has also been revealed from the results of the study that some PLWHA are very assertive of their human rights. People living with the disease are often subjected to unfair discrimination, such as not being taken for a job or promoted or even offered training and development opportunities because of the perception that they carry HIV virus infectious and/or that they may die soon (Deacon et al., 2005).

5.6 Loneliness

According to my findings, loneliness is recognized as one of the peculiar challenges among people living with HIV/AIDS. A culture of privacy has created a tendency to be concerned with issues and ideas that affect an individual. The involvement of the church in the life of most of the respondents living with the disease was anticipated to create a genuine relationship among PLWHA and those not affected by the disease but that has not been the case within the church and the community. The effect of the disease at its peak stage naturally compelled most of the PLWHA to remain alone and always live privately. They prefer to live such a life in order to avoid stigma and shame mostly associated with the

disease. The church activities have caused people living with the disease to be more connected than ever before, yet at the same time people lack real, genuine relationships. All respondents express the common concern that loneliness is a serious and growing issue among people living with HIV/AIDS; however, it is often invisible to the eye of most members in the church. It is a very worrying issue which need to be address which can help to reduce the isolation that most of people affected by HIV/AID experience within the church and the community. There is the need for the church to build a good relationship by creating community gathering among congregational members and PLWHA as a form of socialization in order to build a real relationship that will reduce the stigma and the feeling of isolation by PLWHA. For PLWHA struggling with loneliness, small groups in a form of Bible study group, choir group, youth groups etc can give PLWHA the opportunity to connect with someone else on the basis of their interest in any of the activities from the church. These small groups in the church could be a more appropriate and practical place where relationships can be formed.

5.7 Internal Stigma

The most relevant to shame is internalized stigma, which has been described as encompassing feelings of being inferior, valueless or “less than” others, deserving of or expecting negative outcomes due to having been affected by HIV/AIDS with its association of shame and negative self-image felt by people living with HIV/AIDS (Audet et al., 2013). As a result, shame is often assessed as a component of internalized stigma measures.

This is probably one of the most profound impact of HIV/AIDS-related stigma for people living with the condition is the phenomenon sometimes referred to as “self-stigma” which happens when a person living with HIV/AIDS imposes stigmatizing actions and beliefs on themselves. It should not be surprising that this occurs: people living with HIV are, after all, members of the same cultural, social, and moral communities as many of their “stigmatizes.” They will largely ascribe to the same values and norms, and so have the same ideas about the nature of HIV and what it means about people living with it. However, they additionally have to deal with being the object of the cruel, thoughtless, and hurtful actions of others.

Chapter six

In this chapter, I will draw up conclusion relating to the research and come up with some recommendations which could be relevant to future research, religious institutions, etc.

6.0 Conclusion

The results of the study purely show how HIV/AIDS stigma is experienced by the respondents. Spoiled identity, social relations and the need to manage information emerged as strong themes in this study. Stigma is about social relations. Linking HIV/AIDS with immorality or aberrant lifestyle has the effect of creating in-group and out-group categories or 'we are HIV-negative' and 'they are HIV-positive' groups. For the self-stigmatising HIV-positive person the consequence is facing a less accepting world that includes rejection by family, friends, the congregation and society. This may discourage an affected person not to review his or her status, leading to self-isolation and not seek support from the church, anti-retroviral treatment and the possibility of engaging in unprotected sex.

This research shows that the church is seen as an influential agent in the society and thus has the chance to get involved in the lives of many people. The church trademarks of spirituality and prayer are useful tools for intervention in times of crisis. The Church is considered as an institution that offers care to the people, and the fact that it endures in terms of permanently dwelling in the community makes it possible for it to carry out its ministry.

Unfortunately, some of the role of the church turns to affect negatively among those living with HIV/AIDS in terms of their response to people living with HIV which negatively promote stigmatization and shame. In the opinion of some religious leaders, lending a helping hand to people living with HIV/AIDS could be regarded as condoning the afflicted person's acts. The scripture view of stigma must be considered in relation to the action taken by the church. For instance, people with diseases such as leprosy, which could be related to HIV/AIDS in the bible, were stigmatized and discriminated against, but Christ accepted them without any discrimination, and the Church is thus supposed to emulate Christ in accommodating PLWHA (Emma, 2008). The most disturbing aspect of living with HIV/AIDS is the fear or the experience of being rejected. There is no worse indication than to be told one is being punished for a sin one once committed. HIV/AIDS could just as well be looked on as a contingent phenomenon, a random and unfortunate event that turns people's lives into a tragedy.

Churches that are open, warm and welcoming are a key resource in the response to the epidemic. Welcoming churches enable people living with HIV/AIDS to openly share their stories which help to reduce the stigma and shame attached to it. According to one of the respondents in the study who declared, *“the church is the last place I will like to disclose my status.”* Another respondent expressed her reservations with the church in this manner: *“when it comes to HIV/AIDS, the church suffers from a failure to love. It is an insensitive and judgemental institution that dissociates people living with HIV/AIDS.”* This unfortunate development has forced many people living with the disease to remain silence and have withdrawn from the church and its activities. Although this assertion was made in the late 1980s, stories of AIDS-related stigma and its accompanying shame and discrimination are still happening within our society: the Chinese government recently ruled against a man who was denied a teaching job after his HIV status become known (Jacobs 2010), gay men in the United States are still not allowed to donate blood (Mroz 2010), and about one third of countries in the world prohibit persons living with HIV to enter their borders (McNeil 2009). These few examples serve as an illustration to the prolifically abundant presence of AIDS-related stigma contained in the literature.

Notwithstanding some of the negatives attitudes from the church towards PLWHA, there were other activities of the church that need to be commended in relation to PLWHA. Concerning some of the activities that the local church leaders can do to encourage the congregation to become a healing environment, Shorter & Onyanha (1998) suggest that Christians who treat people living with HIV/AIDS with compassion are engaged in a variety of activities such as home visitation, patient care, providing relief, washing clothes, consoling the bereaved, and assisting in funeral arrangements. These activities mentioned above were some of the actions practiced by the local church in the research area to mitigate the stigma attached to the disease. Furthermore, Chitando (2007), talking about a healing Church in the African context, defines a healing Church as one that is motivated by a spirit of hospitality and acceptance of PLWHA in order to restore them and their relationships: —In fulfilling its task as a healing community in the context of HIV and AIDS in Africa, church leaders must help the Church to recognize the need to become a welcoming and hospitable Church. By offering safe and friendly space to people living with or affected by HIV, the Church goes a long way in healing persons and relationships. For instance, the experience of healing mostly occurs when people affected HIV no longer have to experience exclusion, stigma and shame. According to one of the respondents living with the disease, when they receive love and

acceptance, healing occurs. Healing involve overcoming brokenness and alienation. Soul care becomes necessary for a person to be healed through restoration and reintegration as a sense of belonging. The findings will also impart positively in reducing the stigma and shame surrounding people living with HIV/AIDS through the activities of the church in engaging spiritual support and counselling that could bring hope to people living with HIV/AIDS.

I find commonalities in what causes stigma, the forms in which stigma is expressed, how PLWHA perceived themselves and the role of the church in mitigating the stigma. Therefore, attention is again given to the implications of these findings for the development of interventions intended to reduce stigma and mitigate its impact.

The promotion of anti-retroviral treatment and provision of health clinic from the church, the attitude of some of the local church members and social action and mobilisation has a fundamental role in reducing HIV/AIDS stigma. Up till now, efforts to mitigate HIV/AIDS-related stigma and shame have not adequately matched the magnitude and apparent universality of the problem.

Female PLWHA seem to be one of the vulnerable and marginalized groups, who are facing multiple forms of stigmatized attitudes from the research area. This is due to social and cultural structure, inequalities, injustices, and patriarchal ideologies that impede women to attain high status in the society to be able to take critical decision in their interest. The situation of PLWHA compelled some of them to feel guilty and shame with regard to their HIV status. This type of emotional pressure from the congregation and the family members motivated PLWHA to live in loneliness, experience internal stigma and exposed to social criticism or shame. Internal stigma of PLWHA is an attribute that is significantly discrediting and which, in the eyes of society, serves to reduce the person who possesses it. PLWHA felt they are the dehumanized and debased person.

It is the high time the church adopt new models for counselling, awareness and social or cultural change in our response to deal with HIV/AIDS related stigma and shame. This study has suggested that along with the counselling provided for PLWHA, people attitudes need to be changed in order to reduce internal stigma and to help ensure their role in family and community. Media and education campaigns might help to reduce abusive behaviour and stress among PLWHA and their families. Participatory education campaigns can promote positive understanding of the disease and address the root causes of anxiety, fears and tension relating to contagion and ambivalence about sexual difference and so on

6.1 Recommendation

My intention for this section is to frame some guidelines on how the church could play a positive role for PLWHA experiencing stigma and shame.

6.1.1 Knowledge and fear about HIV/AIDS

The persistence across diverse settings of the “knowing, but not quite believing” that HIV can only be transmitted through three specific routes shows that overcoming these doubts and fears is one of the basic direction for any program gearing to reduce HIV-related stigma. The persistence stigma moved by these fears, despite many years of education, information and communication (EIC) and more recently behaviour change communication (BCC) efforts, shows that current strategies for imparting an understanding of HIV/AIDS virus transmission are not completely effective, and in some situations may be contributing to fear and stigma. More specifically, the findings suggest programmes relating to HIV/AIDS needs to focus on substantive content and the procedure of delivery by taken into consideration the following outline:

6.1.2 Substantive content of messages

Constant fears about HIV/AIDS transmission through improbable means, and the “what if” assumption people create in the face of these fears, show that many people live on and get disturb about HIV/AIDS transmission through casual contacts in daily life. These unfounded fears obviously suggest that partial and often negative information contained in HIV/AIDS-related messaging can have undesirable and unintended consequences. Thus, policies and programs need to broaden and deepen HIV messages by providing information not only on how HIV virus is transmitted, but also how it cannot be transmitted through educational campaign by the church. This includes identifying the most commonly feared “casual” contact situations in the community (example, contact with blood, sweat, and saliva where no fluids are exchanged, or mosquitoes) and explaining why HIV transmission is highly unlikely or impossible through these situations.

Ensuring that people have a deep enough understanding of what HIV is and how it is transmitted so that they are equipped to make correct assessments of actual HIV risk in any given life situation they encounter. For example, understanding that HIV virus is unable to survive for long outside the body will help reassure people that HIV virus cannot be transmitted through various modes of casual contact experienced on a daily basis, such as

sitting next to a person with HIV in the church, on a bus or sharing utensils with a person with HIV. This is very vital information to get across because most people in the research area expressed fear of transmission through casual contact, and many forms of stigma are directly related to that fear.

Delivering clear information by explaining exactly how HIV is transmitted through mother-to-child, blood and sex, to ensure a clear understanding of risky exposures and the relative risks of different exposures.

The ways in which HIV/AIDS can be transmitted are often not presented in a clear terms (sex, blood, mother-to-child), with little distinction made between the relative risks of the three modes or of the relative risks of different kinds of contact within a given mode (e.g., blood exposure through injection or transfusion versus blood left on a nail clipper).

The church in their educational campaign to the congregation could broaden the content of HIV messages to include information on HIV/AIDS beyond transmission, especially, what it means to live with HIV; the skills needed to help individuals prevent its transmission; and if infected, how to live productive and healthy lives. For example, messages could inform about the longevity of a person living with HIV by taking antiretroviral treatment serious in addition to proper diet. Messages also could give practical information on different strategies for bringing up the issue of HIV and condom use with sexual partners, both in casual relationships and steady partnerships.

Creation of improved awareness of what stigma is and fostering an understanding of how stigma is harmful to the affected people, their families, the church and the community would help stop this inadvertent stigma from occurring. At the same time, addressing each individual's role in creating or reducing stigma would generate the necessary will to do something about it understanding of HIV transmission.

People living with HIV/AIDS should be involve as integral members of all programs People affected with HIV/AIDS have a vital role in reducing stigma at any level of intervention and provide a strong basis on which to build successful programs. Bearing **the** brunt of stigma, most people affected by HIV/AIDS have the life experience and knowledge needed to design and implement appropriate response to reducing stigma.

6.1.3 Style and delivery of messages

In addition to the content of HIV and AIDS information, the style and delivery of HIV/AIDS messages to the congregation and the community indirectly fuel the perpetuation of HIV stigma.

In this context, the findings suggest the following vital areas to address in working toward reducing HIV-related stigma by the church: The church should provide HIV/AIDS information in an interactive manner, mediated by a trusted and knowledgeable counsellor or facilitator. This will promote questions, discussion and feedback on the hypothetical scenarios that people get disturb about. Such a pattern enables the facilitator to address all individual concerns and unambiguously dispel the notion that HIV can be transmitted through casual contact. Once people come to believe and understand this, they will be less likely to stigmatize people affected by HIV/AIDS through avoidance and isolation. Conveying of messages relating to HIV/AIDS stigma through posters, fliers, billboards, radio, etc. are relevant but need to be complemented by opportunities to ask questions about the information to dispel any misunderstandings the information creates about casual transmission. A positive image depicting people living with HIV/AIDS should be encouraged instead of fear-based messages and negative images. The findings confirm that the use of fear-based messages that equate people living with HIV/AIDS with suffering, images of sick and death only serve to increase the fear of people living with HIV/AIDS and its associated stigma and shame. Eliminating fear-based and negative imagery will increase positive images of persons living with HIV and fight the fear that drive stigma.

6.1.4 Values, norms, and moral judgments

For stigma to be effectively addressed, policy and programs must attempt to disengage HIV from the sensitive and often taboo social issues that are linked with its transmission, especially sex. This can be done without sacrificing effective communication of information about prevention. For example, Messages, programs and policies need to discuss the behaviours that can lead to HIV transmission without direct reference to specific individuals or groups to ensure that particular groups such as sex workers, women, and young girls are not singled out as agents of transmission. Messages about HIV that include implicit value judgments about behaviour legitimize stigma by implying that HIV is a matter of personal choice.

6.1.5 Involvement of PLWHA in the activities of the church

Churches need to see to it that their activities are inclusive, non-judgmental and marked by compassion. This means that PLWHA should be given the opportunity to get involved in church programmes, which would then encourage and pave way for others in the same situation to break the silence and access testing, support, and care, thereby making the prevention strategy easier, and reducing the stigma and shame associated with people living with HIV/AIDS.

This study has so far revealed that PLWHA are often stigmatized and discriminated against, and that this has led to their exclusion from family, church, and community life. If church leaders in Effiduase Methodist church are to be effective in fighting against HIV/AIDS-related stigma, they should consider PLWHA's role in their church just like anyone else's. This means not merely showing that PLWHA are part of the Church, but going further to allow them to hold key or prominent roles in the church activities, which will add immense value in minimizing HIV/AIDS stigma. In fact, any fight against HIV and AIDS-related stigma which does not involve PLWHA will obviously prove fiasco, since these people have a wide range of experience and knowledge which the Church can use to design HIV and AIDS programmes, and furthermore, they can support each other in bearing the stigma and other challenges PLWHA go through.

6.1.6 Counselling for PLWHA and their families

Since PLWHA are most of the time marginalized in their homes, the Church should create an environment of inclusion and acceptance in such a way that other people in homes and communities learn from the Church how they should accept PLWHA. Hence, the work of church leaders in this situation will include counselling the families, church members, friends, and neighbours of PLWHA in order to stimulate a culture of inclusion. This will help in overcoming common doubts and fears about HIV/AIDS and the tendency to judge PLWHA. The counselling of church members, families and friends of PLWHA should include basic information about HIV/AIDS, open talks, messages about HIV/AIDS and individual as well as group consultation. Church leaders in Effiduase should make use of qualified facilitators to address their churches about HIV/AIDS in a manner that is less stigmatizing for PLWHA.

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INTERVIEW GUIDE

INTERVIEW GUIDE FOR PEOPLE LIVING WITH HIV/AIDS AND LOCAL CONGREGATION AT EFFIDUASE IN THE EFFIDUASE/SEKYERE DISTRICT, GHANA

I am Joyce Antwi, a Master student of VID Specialized University, Norway, conducting a research on “Stigmatization and shame in HIV/AIDS: assessing the role of Methodist church with people living with HIV/AIDS in Effiduase, Ghana”. This study is purely for academic purpose. Therefore, information and identity of respondents will be treated as confidential when respondents concerns are given.

Date.....

Interview guide for people living with HIV/AIDS

1. I would like to get to know you a little, can you tell me about yourself?.....
2. How did you react upon hearing your status? And why that reaction?.....
3. At the moment, do you experience any difficulties in your life? How has your local congregation contributed to those difficulties in any way?.....
4. Has your local congregation contributed positively in your situation?.....
5. Has your local congregation contributed negatively in your situation?.....
6. What are you expecting from your local congregation?.....
7. How are you coping with the disease?.....

Interview guide for church leaders

8. What is the official position of the church towards people living with HIV/AIDS and of the local congregation?.....
9. Are you talking about HIV/AIDS in your congregation? In case yes: in what circumstances? If no, why do you think you are not talking about it?.....
10. What is the congregation doing in relation to stigma and shame towards people living with HIV/AIDS?

11. How do you think that the congregation contribute to empower people living with HIV/AIDS?.....

12. How are the church members coping with people living with HIV/AIDS?.....